Development and validation of the 'Pathways To Healthcare Questionnaire' (PaTH-Q) A measure of psychosocial factors influencing symptom appraisal and help-seeking behaviour for potential symptoms of cancer

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Development and validation of the 'Pathways To Healthcare Questionnaire' (PaTH-Q): A measure of psychosocial factors influencing symptom appraisal and help-seeking behaviour for potential symptoms of cancer

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Declaration

I, Sonja Kummer, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated.

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This thesis is dedicated to Mimi who is deeply missed.

Abstract

The time from a patients' first awareness of symptoms to the first presentation to a healthcare professional often constitutes the greatest proportion of the time to diagnosis of cancer. This research aimed to develop and validate a theory-based questionnaire (the 'Pathways To Healthcare Questionnaire'; PaTH-Q), to determine the factors that contribute to patients' decision to seek help.

Study One: A systematic review to determine how studies have measured psychosocial factors affecting time to presentation for [potential] cancer symptoms. Results indicated that the majority of studies (n = 36) were atheoretical and failed to use valid and reliable tools to measure psychosocial factors which may influence help-seeking behaviour.

Study Two: A secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms and decision to seek help. The study examined whether responses given by (n = 49) interviewees, who had sought help for [potential] symptoms of cancer, can be classified according to contributing factors within the appraisal interval of the Model of Pathways to Treatment (Scott et al., 2013).

Study Three: Generation of items for the PaTH-Q was informed by the findings of Study One and Study Two. Content validity of the questionnaire was supported by subscale and item content validity index. Cognitive interviewing indicated that the PaTH-Q was interpreted as intended.

Study Four: Initial psychometric testing of the PaTH-Q via a retrospective cross-sectional study with individuals (n = 50) previously diagnosed with cancer. Although further work is required to adequately establish the psychometric properties of the PaTH-Q, the study highlighted that the PaTH-Q shows at least acceptable validity and reliability for some of the subscales.

Overall, the findings indicate the need for valid and reliable measures, informed by theoretical models, to systematically determine the factors that contribute to symptom appraisal and the decision to seek help.

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Chapter 1 : Early Presentation and Diagnosis in Cancer: An overview

1.1 Introduction

The aim of this PhD thesis was to develop and validate a theory-based questionnaire that can be used with patients who have sought help for potential symptoms of cancer, in order to assess the factors that contributed to their decision to seek help. As such, the 'Pathways To Healthcare Questionnaire' (PaTH-Q) was developed. Specifically, the PaTH-Q focuses on how heuristics and 'cognitive reasons to consider help-seeking' affect symptom appraisal and the decision to seek help.

This chapter aims to provide an overview of early presentation and diagnosis in cancer, as well as the theoretical and methodological issues in early diagnosis research. It also addresses the aims of the PhD thesis and outlines the chapter structure of the thesis.

1.2 Background

1.2.1 Early Presentation and Diagnosis in Cancer

Cancer (when abnormal cells divide in an uncontrolled manner and may eventually form a benign or malignant tumour) (Macmillan Cancer Support, 2015) can lead to significant morbidity and mortality. In the UK 356 860 new cases of cancer were diagnosed in 2014 (Cancer Research UK, 2015a) and approximately 14.9 million new cases were diagnosed worldwide in 2013 (Global Burden of Disease Cancer Collaboration, 2015). There were around 163 444 cancer deaths in the UK in 2014 (Cancer Research UK, 2015a) and 8.2 million worldwide in 2013 (Global Burden of Disease Cancer Collaboration, 2015).

Reducing cancer mortality and increasing survival rates by improving prevention, promoting early diagnosis and screening, and guaranteeing treatment and care was identified in the first 'NHS Cancer Plan' in 2000 (Department of Health, 2000). This plan was further reinforced by the 'Cancer Reform Strategy' (Department of Health, 2007), 'Improving outcomes: a strategy for cancer' (Department of Health, 2011) and more recently with 'Achieving world-class cancer outcomes: a strategy for England 2015-2020' (Independent Cancer Taskforce, 2015). The latest report, published by the Independent Cancer Taskforce (2015), which sets out a proposed new five-year Cancer Strategy for England, acknowledged that cancer survival rates across most cancer types are lower in England compared to many European countries (Coleman et al., 2011). The International Cancer Benchmarking Partnership (ICBP) which comprises 6 countries (Australia, Canada,

Denmark, Norway, Sweden and the UK) and 12 jurisdictions found that the UK (and Denmark) had the lowest survival rate for colorectal, lung, breast and ovarian cancer for patients diagnosed between 1995 and 2007. The only exception is breast cancer for which the gap is narrowing (Coleman et al., 2011).

It has been suggested that one of the factors driving those differences in survival may be differences in stage at diagnosis (Walters et al., 2013). Later stages at diagnosis (when tumours are invading adjacent structures or spread to distant organs i.e. stages III and IV) have worse prognoses than early stage cancer (when abnormal cells are present but have not spread to nearby tissues i.e. stages I and II). For example, for breast cancer (the UK's most common cancer with 55 222 new cases in 2014), prostate cancer (second most common cancer with 46 690 new cases in 2014) and lung cancer (third most common cancer with 46 403 new cases in 2014) (Cancer Research UK, 2015b, 2015c, 2015d), if individuals are diagnosed with Stage 1 for breast and prostate cancer almost everyone will survive prostate cancer, around 99% will survive breast cancer and 43% to 73% will survive non-small cell lung cancer (Stage 1A and 1B combined) for 5 years or more following diagnosis. However, survival rates decrease the later cancer is diagnosed. When diagnosed at Stage 4 only 15% (15 out of 100 women) diagnosed with breast cancer, 30% (30 out of 100 men) diagnosed with prostate cancer and 2% to 13 % (2 to 13 out of 100 people) diagnosed with lung cancer will survive their cancer for 5 years or more following diagnosis (Cancer Research UK, 2015b, 2015c, 2015d). The Independent Cancer Taskforce (2015) noted that survival may be enhanced by early diagnosis, namely recognising bodily changes, prompt help-seeking and efficient diagnostic services. This thesis focuses on timely presentation of symptoms to a healthcare professional (also known as the patient interval). It has been found that interval lengths vary by cancer. For example, for breast, prostate and lung cancer the mean patient interval was found to be 32, 47 and 33 days respectively. The cancer with the longest patient interval is cervical cancer (of which there were 3 224 new cases in 2014; Cancer Research UK, 2015e) where a mean of 77 days has been recorded (Lyratzopoulos, Saunders, Abel, McPhail, Neal, & Wardle, 2015).

Consequently, a greater understanding of the pathways to cancer diagnosis, such as the timing and reasons for help-seeking behaviour, is critical if later stage at cancer diagnosis is to be reduced and survival from cancer is to be improved (Walter et al., 2012).

1.2.2 Early Diagnosis and Theoretical Issues

Kerlinger (1986) defined theory as "a set of interrelated constructs (concepts), definitions and propositions that present a systematic view of a phenomena by specifying relations among variables, with the purpose of explaining and predicting phenomena" (p. 9). According to Lippke and Ziegelmann (2008) theories are important to define and understand health behaviour mechanisms, advance knowledge, and generate empirical evidence. Similarly, Michie, Rothman, and Sheeran (2007) suggested that the presence of theory in health psychology enables causal associations between variables to be specified, which can then lead to the design of health promotion/behaviour change interventions. Despite the advantages of theory-based research and interventions, only a minority of publications in health psychology appear to base their research or interventions on theory. For example, Painter, Borba, Hynes, Mays, and Glanz (2008) who examined the use of theory in health psychology over the span of five years (2000 – 2005) found that only 69 out of 193 eligible publications mentioned theory. Out of these, 41 were informed by theory, 15 applied theory, five tested the theory and eight intended to build a theory. Similarly, a review of 34 randomised controlled trials of behavioural interventions for obese adults at risk of cardiovascular disease showed that less than half of the included studies (44%) reported a theoretical basis for intervention development, 33% did not state why a certain theory was chosen and all of the reviewed studies failed to outline how theory led to the development of an intervention or offered a systematic rationale underpinning intervention development. A lack of theory is problematic as it not only hinders the advancement and evaluation of any type of research, but also restricts progress within a particular field (Kaptein & Weinman, 2004). With regard to interventions, it has been argued that when an intervention design is not underpinned by an actual theory it is based on implicit theories. Implicit theories may lack psychological processes that are essential to behaviour change and as such they will not only fall short of creating a behaviour change, but findings might also not be generalisable if the processes that caused change are unknown (Michie & Abraham, 2004).

Furthermore, it has been suggested that a change in health behaviour is more likely to occur if interventions are informed by theory (Noar & Zimmerman, 2005). However, to date it remains questionable whether theoretically underpinned interventions do indeed result in more favourable outcomes. Greaves et al. (2011) who conducted a systematic review of reviews to determine whether intervention elements are linked to an increased change in

physical activity and/or diet in individuals at risk of Type 2 diabetes revealed mixed findings. Interventions that were informed by theory were not more likely to result in change than interventions that were not based on theory. The authors argued that these mixed findings may be due to a range of factors. Firstly, behaviour change techniques may not be carried out in a precise enough manner or they may not accurately represent the specified theory and as such it may be difficult to establish the usefulness of certain theories or behaviour change techniques underpinning/informing interventions. Secondly, none of the reviews included in the study considered whether the intervention was conducted as planned (also known as intervention fidelity). Consequently, it was suggested that the absence of a significant relationship between a certain theory and the outcome effectiveness of interventions may be due to the absence of good theories or because the theories were not adequately implemented.

It has been noted by Scott and Walter (2010), Scott, Walter, Webster, Sutton, and Emery (2013) and Walter et al. (2012) that the majority of studies concerning help-seeking for cancer have failed to incorporate existing theories. However, if the causes for delayed presentation are to be adequately understood, assessed and targeted, then theoretical models ought to underpin all studies (Andersen, Vedsted, Olesen, Bro, & Sondergaard, 2009; Scott et al., 2013; Walter, Humphrys, Tso, Johnson, & Cohn, 2010). In addition to this, theory could inform research into help-seeking behaviour to enhance existing knowledge, and to develop and test hypotheses (Scott & Walter, 2010). Applying socio-psychological models also provides researches with quantitative data which ultimately enables possible variations in response to cancer symptoms between different cancer types or between different populations to be studied (de Nooijer et al., 2001a). de Nooijer et al. (2001a) suggested that the association between a range of psychosocial factors such as symptom interpretation and knowledge or fear and trust could be tested by applying concepts from numerous socio-psychological models, such as Leventhal's fear and danger control (Leventhal, 1970), perceived benefits or perceived barriers outlined in the Health Belief Model (Becker & Rosenstock, 1984) or the Attitude Social Influence-Self-Efficacy model (de Vries, Dijkstra, & Kuhlman, 1988; Vries & Mudde, 1998). Even though a range of models were postulated by de Nooijer et al. (2001a), until recently research in this area was predominantly atheoretical, with the exception of one model, specifically the General Model of Total Patient Delay or more commonly known as the Andersen Model (Andersen, Cacioppo, & Roberts, 1995), which has been applied to help-seeking research. The model

describes five stages in which delay can take place, ranging from misinterpreting symptoms (appraisal delay), self-management of symptoms (illness delay), failing to make an appointment with a healthcare professional (HCP; behavioural delay) and difficulties in getting an appointment (scheduling delay) to treatment delay (see **Figure 1**).

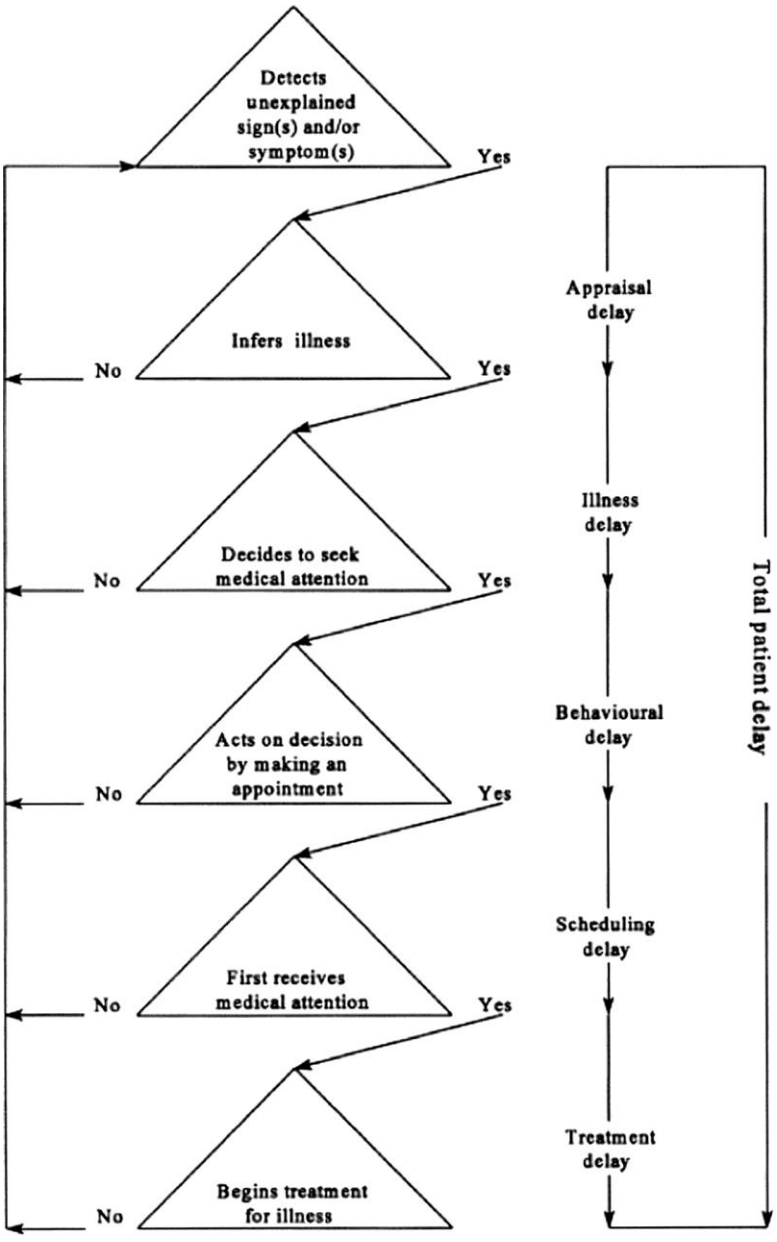

Figure 1 General Model of Total Patient Delay (Andersen et al., 1995)[1]

[1] Reprinted by permission from John Wiley & Sons Inc.: British Journal of Social Psychology, Andersen et al., copyright 1995

The Andersen Model depicts help-seeking behaviour as a linear process where individuals pass through the stages in a sequential order. However, contrary to Andersen et al. (1995), Scott et al. (2013) instead suggested that help-seeking may be a more dynamic and complex process. For example, although an individual may initiate help-seeking behaviour by becoming aware of bodily changes, there may not be a precise starting point in the pathway to diagnosis. Individuals can either enter the pathway to diagnosis via the asymptomatic screening route or they may present with vague or numerous symptoms. Even if individuals present with symptoms they can still move 'forward' and 'backwards' through the help-seeking process. This is because a diagnosis may not be made, treatment may be ineffective, unavailable or not offered, or symptoms may have to be monitored and help-seeking behaviour re-evaluated if symptoms continue or change (Scott et al., 2013).

There has also been little evidence for the presence or importance of some stages within the Andersen Model, for example behavioural and scheduling delay (Molassiotis, Wilson, Brunton, & Chandler, 2010). Given that stages tend to correspond with one another it has been proposed that certain stages could be ignored or combined (de Nooijer et al., 2001a; de Nooijer et al., 2001b). Findings from a systematic review that examined the application of the Andersen Model in studies that assessed cancer diagnosis revealed support for the appraisal and treatment delay, as well as some evidence for scheduling delay. Nevertheless, it was difficult to make an adequate distinction between illness delay and appraisal delay. It was also unclear whether behavioural delay can indeed be classified as a separate stage (Walter, Webster, Scott, & Emery, 2012).

Furthermore, various researchers have criticised the term 'patient delay' first defined by Pack and Gallo (1938) as "the time elapsing between the onset or discovery of symptoms and the first visit to a physician" (p. 443). It has been argued that 'patient delay' is a value laden term and should therefore be disused (Walter et al., 2012). This critique is similar to a notion highlighted by Dobson, Russell and Rubin (2014) who remarked that characterising patients as 'delayers' places the culpability onto the patient, something that is likely to be stigmatising. For example, many patients may not deliberately postpone help-seeking due to a lack of realisation that they are indeed ill (Corner, Hopkinson, & Roffe, 2006). Also, as noted by Turris and Finamore, (2008) some patients do not postpone help-seeking, but seek help straightaway or within an adequate period of time. The proposition to reject the

term ‘patient delay’ has been endorsed by numerous researchers (Scott & Walter, 2010; Weller et al., 2012) who have stressed the importance of clear, suitable and reliable definitions and terminology. In line with this, for the purpose of this PhD thesis the term ‘time to presentation’ (TTP), which describes the time from first noticing a bodily change to the first consultation with a HCP, will be used instead of patient delay.

1.2.3 The Model of Pathways to Treatment

Given the limitations of the Andersen Model (Andersen et al., 1995), Walter et al. (2012) and Scott et al. (2013) have proposed a modified framework, known as the Model of Pathways to Treatment (MPT) (Scott et al. 2013; see **Figure 2**), which provides a theoretical framework for future studies investigating the pathways to cancer diagnosis. So far, the model has been used to explore the pathways to diagnosis for a variety of cancers, such as lung cancer (Birt et al., 2014), colorectal cancer (Hall et al., 2015), breast cancer (Marcu, Lyratzopoulos, Black, Vedsted, & Whitaker, 2016; Moodley, Cairncross, Naiker, & Momberg, 2016), melanoma (Walter et al., 2014), as well as in a study that investigated symptom appraisal and help-seeking behaviour in a variety of cancers (Emery et al., 2013a, 2013b). The MPT has also been used in studies of other conditions, such as gout (Liddle et al., 2015) and diabetes (Usher-Smith, Thompson, Zhu, Sharp, & Walter, 2015). The MPT suggests that the pathways to treatment are comprised of ‘events’, ‘processes’, and ‘intervals’, the timing of which are influenced by ‘contributing factors’, the latter of which could be associated with the patient (e.g. previous experience, cultural, social, psychological, demographic, comorbidities), the HCP/system (e.g. healthcare access, policy and delivery) or the disease (e.g. location, size or growth rate).

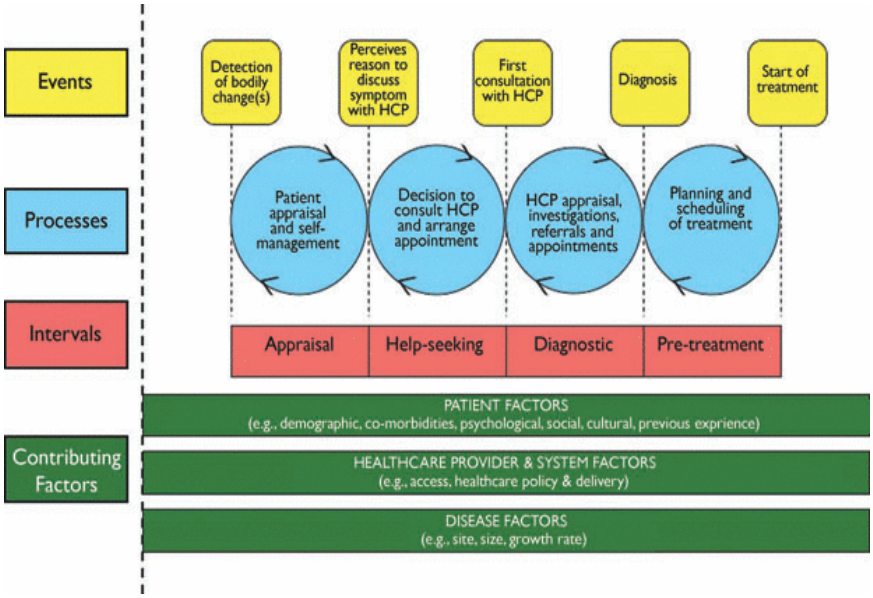

Figure 2 Model of Pathways to Treatment (Scott et al., 2013)[2]

In the MPT 'events' are defined as the key time points in the pathways to treatment and entail:

1. 'detection of bodily change(s)' [time point when a person becomes aware of somatic information],
2. 'perceives reason(s) to discuss symptom with a HCP' [time point at which a person believes they have a motive to consult a HCP about their symptom, and thus considers seeking help from a HCP],
3. 'first consultation with a HCP' [initial discussion of symptoms with a HCP]
4. 'diagnosis' [timing of a formal diagnosis],
5. 'start of treatment' [initiation of curative or palliative management of symptoms].

'Intervals' refer to the time periods between events and consist of the:

1. **'Appraisal' Interval.** The time between first detecting a bodily change to perceiving a reason to discuss symptoms with a HCP. Individuals will evaluate their bodily changes and may self-manage their condition (e.g. with over the counter medication) rather than seeking-help from a HCP.
2. **'Help-seeking' Interval.** The time between first perceiving a reason to discuss symptom with a HCP to initial discussion of symptoms with a HCP. Perceiving a

[2] Reprinted by permission from John Wiley & Sons Inc.: British Journal of Health Psychology, Scott et al., copyright 2013

reason to discuss a symptom with a HCP does not mean that an individual will indeed seek help, as help-seeking may be hindered by external factors such as access to healthcare, or beliefs about the consequences of seeking help.

3. **'Diagnostic' Interval.** The time between the first appointment with a HCP and the formal diagnosis being made. The diagnostic interval is the time between the initial discussions of an individual's presenting history, symptoms, signs, and other risk factors in order to formulate a possible diagnosis. During this interval appointments and investigations are carried out depending on the availability and arrangement of the health care system, as well as the individual's willingness to do so.
4. **'Pre-treatment' Interval.** The time between the formulation of a diagnosis and commencement of treatment. This interval also depends on the availability and arrangement of the health care system, as well as the individual's input and decisions. However, at times this interval may not occur as treatment may not be available or accepted.

The MPT (Scott et al., 2013) integrates cognitive, emotional, behavioural or structural 'processes' and their 'contributing factors' (such as patient, healthcare, system or disease factors) within each interval. The remainder of this introduction will focus on further explaining the factors that contribute to the 'appraisal' and 'help-seeking' intervals given that together they form TTP. Furthermore,

1.2.4 Contributing factors in the appraisal interval

The appraisal interval involves becoming aware of bodily change(s). Physiological changes can be due to fluctuations in normal bodily processes, disease (acute and chronic), emotions or environmental conditions. Such physiological changes will then activate receptors throughout the body which generate information about an individual's bodily functions and state. However, only a minimal amount of this information will shift a person's attention to bodily changes and will be consciously processed. Attention regulation determines to what extent somatic information is selected for further processing. Consequently, being aware of mild and ambiguous symptoms depends on the attention an individual pays to it or can pay to it (Kolk, Hanewald, Schagen, & Gijsbers van Wijk, 2003). Once symptoms are noticed, a process of appraisal or interpretation takes place. According to (Mechanic, 1978) there are four symptom characteristics that govern

an individual's response to symptoms, as symptoms alone are not sufficient to warrant help-seeking:

1. Visibility of symptoms – individuals are more inclined to seek help for symptoms that are visible than ones which are not.
2. Severity of symptoms – if a symptom is perceived to be serious the more likely it will be interpreted as requiring action.
3. Interference of symptoms with daily living – if symptoms are interpreted as interfering with one's life then help-seeking will be more likely to be initiated
4. Frequency and persistence of symptoms – if symptoms are perceived to be severe and continuous then there will be an increased tendency to seek help.

Dingle (1973) followed 443 individuals over a period of 10 years and noted that there were approximately 10 occurrences per person-year in which the participants reported that symptoms were eventually interpreted as illnesses. Nevertheless, medical help-seeking was only sought for a minority of the illnesses. These early findings on symptom occurrence and subsequent help-seeking behaviour led to the term 'symptom iceberg' [the occurrence of symptoms in the community which individuals perceive as serious, but do not seek professional medical care for (Hannay, 1979)] or the 'iceberg of morbidity' (Verbrugge & Ascione, 1987). To ascertain the size of the 'symptom iceberg' in the UK, a community study of 2 474 adults revealed that over three-quarters of participants reported at least one symptom during the previous two weeks, with individuals each having an average of three to four symptoms (McAteer, Elliott, & Hannaford, 2011). For almost half of all reported symptoms, participants chose to do nothing at all over the two week period. Approximately one third of symptoms resulted in self-management of illness, usually involving over-the-counter medicine use. Only 12 per cent of symptoms led to a consultation with a primary care health professional, such as a GP (Elliott, McAteer, & Hannaford, 2011).

Furthermore, Scott et al. (2013) suggest that existing theoretical models such as the Common Sense Model of Illness Self-regulation (CSM) (Leventhal, Nerenz, & Steele, 1984) can help to identify the 'contributing factors' to the processes of symptom interpretation and self-management that may occur within the appraisal interval.

According to the CSM (Leventhal et al., 1984) individuals generate cognitive representations of symptoms to regulate emotional responses and to guide coping

responses, such as whether or not to seek help [Chapter Three provides a more detailed description of how the various elements of the CSM can help to further explain the processes in the appraisal interval]. In support of this, research examining the factors associated with longer TTP suggests that low symptom awareness and patients' attribution of symptoms to common/minor illnesses, lack of recognition of the seriousness of symptoms and use of self-medication has shown to be a major determinant of prolonged TTP (Bish, Ramirez, Burgess, & Hunter, 2005; Macdonald, Macleod, Campbell, Weller, & Mitchell, 2006; Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Mitchell, Macdonald, Campbell, Weller, & Macleod, 2007; Richards, Smith, Ramirez, Fentiman, & Rubens, 1999).

It has been suggested that people with low cancer awareness are more likely to delay seeking medical help for suspicious symptoms (Macleod et al., 2009). Systematic reviews that have examined patient factors in help-seeking for symptoms of common cancers have shown that one of the leading causes of delayed presentation is lack of awareness, for instance an inability to interpret the symptom as suspicious (Macdonald et al., 2006; Mitchell et al., 2007; Ramirez et al., 1999). Awareness of cancer warning signs has also shown to be low in community based research studies when recall (open-ended) questions were used and higher with recognition (closed) questions (Robb et al., 2009; Waller et al., 2009). The authors also noted that a lower awareness was prevalent in individuals from lower socioeconomic status (SES) groups or ethnic minorities. Further, a recent systematic review that explored influences of cancer symptom knowledge, beliefs and barriers on cancer symptom presentation in relation to socioeconomic deprivation found that overall symptom knowledge, especially for vague symptoms, was lowest and actual presentation time was longest amongst people in lower SES groups (McCutchan, Wood, Edwards, Richards, & Brain, 2015).

There is also evidence of longer TTP associated with vague rather than classic and well known/easily recognised symptoms (e.g. a lump) (Macleod et al., 2009) or alarm symptoms. A cross-sectional study of 1 724 subjects not diagnosed with cancer, which aimed to investigate attributions of potential cancer alarm [physical signs or symptoms that may forecast serious, often malignant, disease (Jones, Latinovic, Charlton, & Gulliford, 2007)] and non-alarm symptoms experienced in everyday life, highlighted that more than a third of participants who reported a cancer alarm symptom in the past 3 months had not sought medical care; symptom severity, such as persistent unexplained pain, symptom

interference and concern, and unexplained symptoms (i.e. a lump) were associated with a perceived need to contact a GP about the symptom (Whitaker, Scott, Winstanley, Macleod, & Wardle, 2014). Other researchers have revealed similar findings. A postal questionnaire study that surveyed 2 371 patients with 15 different cancer types revealed that individuals who had not realised that their symptoms were serious were twice as likely to have taken more than three months to seek help from a doctor (Forbes, Warburton, Richards, & Ramirez, 2014). When individuals thought that help-seeking was not warranted, self-management techniques such as self-medication or symptom monitoring have been found to be a common response to symptoms. For instance, a qualitative study of 26 women, recruited via a screening questionnaire distributed in community settings and online, which aimed to examine women's interpretation of potential gynaecological cancer symptoms, revealed that women were more likely to self-manage symptoms if symptoms were not attributed to an illness (Low, Whitaker, Simon, Sekhon, & Waller, 2015). Likewise a systematic review on psychosocial factors that influenced men's help-seeking behaviour found that participants had a tendency to attribute bodily changes to benign illnesses and usually self-monitored symptoms until they worsened (Fish, Prichard, Ettridge, Grunfeld, & Wilson, 2015).

In recent years there have been a number of policy-led campaigns and initiatives that have focused on improving early diagnosis of cancer in the United Kingdom. Of particular importance are the National Awareness and Early Diagnosis Initiative (NAEDI), announced in the 'Cancer Reform Strategy' (Department of Health, 2007). The NAEDI pathway, proposed in 2009 (Richards, 2009), offered a framework for testing hypotheses related to late stage diagnosis and its consequences. Specifically, the updated NAEDI hypothesis outlined a variety of elements that can influence cancer survival and early mortality (Hiom, 2015). One of these elements "Difficulty accessing primary care" (Hiom, 2015, p. S2), was hypothesised to be due to reduced public awareness, negative beliefs about cancer and barriers to seeking help. As part of NAEDI, the 'Be Clear on Cancer' campaigns, led by the Department of Health (Department of Health, 2011), aimed to raise public awareness of potential signs and/or symptoms of cancer, and to encourage people experiencing these symptoms to see their GP without delay. The success of the campaign seems questionable to a certain degree as indicated by findings highlighted in numerous studies. For instance, Hughes-Hallett, Browne, Mensah, Vale, and Mayer (2016) who assessed the effect and durability of the 'Be Clear on Cancer' 'Blood in Pee' campaign found that although there

was a 92% increase in haematuria referrals during and immediately after the campaign this increase did not result in a significant increase in cancer diagnosis. Similar findings were found by Peacock, Clayton, Atkinson, Tierney, and Lund (2013) who evaluated the impact of the campaign on bowel cancer services. Rather, the authors found that the percentage of colorectal cancers and polyps detected decreased after the campaign was launched, and that there was no absolute change in the stage of colorectal cancer at presentation. The only successful campaign appeared to be the one for lung cancer where a 3.1% increase of small-cell lung cancer diagnosed at stage one was observed (Ironmonger et al., 2015). The increase of public awareness for the 'Blood in Pee' campaign also seemed to be relatively short lived as referral levels appeared to drop to baseline less than six months after the campaign ended (Hughes-Hallett et al., 2016). It could be concluded that raising awareness alone does not necessarily translate into improvement in timely cancer diagnosis. Rather, it can be argued that the findings observed from these three campaigns appear to have caused an increase in the 'worried well' presenting to hospital (Peacock et al., 2013) instead of successfully managing to diagnose a large number of individuals.

1.2.5 Contributing factors in the help-seeking interval

In line with Bandura's Social Cognitive Theory (SCT) (1986; 1997) an individual's decision to seek help after perceiving a reason to discuss a symptom with a HCP is dependent upon their self-efficacy [a person's perceived ability to discuss the symptom and seek help.], outcome expectations [e.g. a person's belief about what may happen should they decide to seek help], as well as their short- and long-term goals.

In the SCT self-efficacy can be influenced by healthcare system barriers or personal barriers. For instance, in a recent UK survey of barriers to presentation in 1 986 individuals the most frequently cited healthcare system barriers were difficulty getting an appointment at a suitable time and difficulty getting an appointment with a particular doctor (Moffat, Hinchliffe, Ironmonger, & Osborne, 2016). Regarding the importance of competing priorities for goals on help-seeking behaviour, individuals have frequently been found to prioritise other aspects of their life over their symptoms (Scott et al., 2008), such as vacation, employment and family issues (Burgess, Hunter, & Ramirez, 2001; Emery et al., 2013a; Moodley et al., 2016; Walter et al., 2014), moving home and other health concerns (Walter et al., 2014).

Outcome expectations (social, physical and self-evaluative) also play a role. Social outcome expectations consist of social reactions or sanctions that may impact help-seeking

behaviour (Scott et al., 2013). For example, individuals are often reluctant to seek help due to worry about wasting the doctors' time. Cromme et al. (2016) who conducted a community based qualitative interview study with 62 indivduals experiencing persistent cancer symptoms found that participants thought that seeking help for symptoms that were not serious enough (i.e. persistent, worsening or life-threatning) would waste the doctor's time. Consequently, some participants noted that they did not tell their doctor about less serious symptoms. Rather, a vast amount of participants only considered seeking help when symptoms were indeed worsening or persistent. Similar findings regarding indivduals' perception about wasting their doctor's time have been found in other studies (e.g. Emery et al., 2013a; Low et al., 2015; Whitaker et al, 2014) as well as in a qualitative synthesis on patients help-seeking experiences and delay in cancer presentation (Smith, Pope, & Botha, 2005).

Substantial research has been carried out regarding the role of emotions. Whilst emotional responses to initial symptoms may prompt seeking help, emotions related to outcome expectations of seeking help may act as a barrier (Balasooriya-Smeekens, Walter, & Scott, 2015). In a qualitative synthesis by Smith et al. (2005) fear of unpleasant treatment was identified as a key determinant of longer TTP, especially among individuals with breast and testicular cancer. A systematic review of barriers to early presentation and diagnosis with breast cancer among black women (Jones et al., 2014) and a systematic review by Macleod et al. (2009) also noted that fear of investigations, and fear of diagnosis or treatment contributes to prolonged help-seeking. Negative emotions, such as worry what the doctor might find has also been linked to later presentation in lower SES groups (McCutchan et al., 2015).

To conclude, although there is support for these theories in existing research it is not conclusive. This is because it is currently not known which factors are most important or which lead to most delay in presentation. It is also unclear why some factors act as barriers and/or triggers. Further, studies have often only looked at one element or have used different measures, therefore prohibiting effective comparisons to be made.

1.2.6 Early Presentation and Methodological Issues

Cancer diagnostic research has been characterised by a lack of consensus on terminology and definitions, and other methodological issues. For instance, help-seeking behaviour has frequently been measured using a range of different methods and has predominantly relied upon retrospective data collection (Scott & Walter, 2010).

Given the methodological challenges within this area of research, a consensus working group (CWG) developed numerous recommendations for methodological approaches in early diagnosis research and published the Aarhus Statement, a checklist (see **Table 1**) that researchers can use when designing and conducting studies (Weller et al., 2012). The guideline aims to encourage better consistency and transparency in methods and measurements, in addition to providing a resource for researchers who are developing studies that measure or map the pathways to diagnosis.

Table 1 The Aarhus checklist (Weller et al., 2012)[3]

Item		**Y/N**
DEFINITIONS OF TIME POINTS AND INTERVALS		
1	For studies requiring the measurement of an interval, are the beginning and end points of this interval clearly defined?	
2	For all time points and intervals described, are there precise, transparent and repeatable definitions, and is the complexity of time points such as the date of first symptom and date of first presentation addressed?	
For studies that require an estimate of the date of first symptom:		
3	Do the researchers refer to a theoretical framework underpinning definition of this time point?	
4	Is there a discussion of the different biases influencing measurement of this time point?	
For studies that require measurement of a date of first presentation to healthcare:		
5	Do the researchers discuss the complexity of the date of first presentation?	
For studies that require measurement of a date of referral:		
6	Do the researchers discuss the nature of the referral and provide adequate detail – for example, whether it was for investigation or consultation by a colleague in secondary care?	
For studies that require measurement of the date of diagnosis:		
7	Do the researchers use an existing hierarchical rationale for the date of diagnosis measurement?	
MEASUREMENT		
8	Is the healthcare context in which the study is based fully described?	
9	Do the questions on time points and/or intervals clearly derive from stated definitions?	
10	Do researchers acknowledge the need for theoretical validation and make reference to the theoretical framework(s) underpinning measurement and analysis of the time points?	
For studies using questionnaires and/or interviews with patients and/or health-care providers:		
11	Has a validated instrument been used?	
12	Have the researchers included a copy of their instrument?	
13	Is there some discussion of how reliability and validity (trustworthiness) has been established?	
14	Do researchers acknowledge the need for theoretical validation and make reference to the theoretical framework(s) underpinning measurement and analysis of the time points?	
15	Is there discussion of the different biases influencing measurement of the time points,	

[3] Adapted by permission from Macmillan Publishers Ltd on behalf of Cancer Research UK: British Journal of Cancer, Weller et al., copyright 2012

	such as how and when the question is asked and who is being asked?
16	Is the timing of the interview in relation to the date of diagnosis provided?
17	Is there any triangulation of self-reported data with other data sources such as case notes?
18	Is data analysis described in full including how and why data are categorised, how missing and incomplete data are managed, and how outliers at both ends of the spectrum are accounted for?
For studies using primary case-note audit and database analysis:	
19	Case-note analysis: is there a clear and precise description of how case-note data were used to ascertain time points with an acknowledgment of limitations of such data?
20	For database analysis: is there a thorough description of the database chosen including sampling coverage and completeness of information?

Furthermore, Andersen et al. (2009) have argued that at present, the causes of delayed presentation cannot be effectively determined due to the absence of validated and reliable measures of the potential contributing factors. Nevertheless, on the whole, as can be seen from the brief overview outlined below, reliability and validity are a principal element in measurement and data generation (Oppenheim, 1992).

1.3 Reliability

Reliability is defined as the degree to which any measurement produces the same results on a recurrent basis (Nunnally, 1978; Bollen, 1989). Reliability is a prerequisite for validity, but high reliability does not necessarily equate to high validity (Nunnally, 1978). Bollen (1989) highlighted that reliability refers to the part of the measure that is free of random error. Random error may be due to a participant's mood, the way a questionnaire is administered or the instructions given to participants (Nunnally, 1978).

1.3.1 Test-retest reliability

Test-retest reliability is the degree to which test scores are consistent under the same conditions. One of the major challenges of test-retest reliability is how much time is acceptable between the first and second administration. If there is too much time between the two administrations it may be likely that external circumstances influence responses for the second administration. Whereas, if there is too little time between the two administrations it is possible that answers in the second administration will be similar to those in the first administration (Streiner, Norman & Cairney, 2015).

1.3.2 Internal consistency reliability

Internal consistency is the extent to which items in a questionnaire correlate with each other, therefore measuring the same construct (Terwee et al., 2007). Terwee et al. (2007)

note that an internally consistent measurement is achieved through adequate definition of the construct being measured, satisfactory items and factor analytic techniques. There are a number of different ways to calculate internal consistency, namely Kuder-Richardson, split halves or Cronbach's alpha. However, Cronbach's alpha is most commonly used. A more detailed discussion of internal consistency and its application can be found in Chapter Five.

1.3.3 Parallel forms reliability

Parallel forms reliability is used to determine the reliability of the results of two tests that were created in the same manner from the same content domain. To determine parallel forms reliability a large set of questions that address the same construct will be generated. This set of questions will then be divided into two sets which are administered to the same sample of individuals. The estimate of reliability will be the correlation between the two parallel forms (Trochim, 2006).

1.3.4 Inter-rater reliability

Inter-rater reliability is the degree of agreement between two or more raters who provide consistent estimates of the same behaviour (Trochim, 2006). Inter-rater reliability can be determined via two different methods, depending on whether a measure is categorical or continuous. If a measure is categorical, raters will check which category each observation will belong to and their percentage of agreement will be calculated. If a measure is continuous the correlation between the ratings of the two raters will be calculated (Trochim, 2006).

1.4 Validity

Validity is defined as the extent to which an instrument measures what it is meant to measure (Cronbach, 1951; Nunnally, 1978).

1.4.1 Content validity

Content validity aims to establish whether the items in a questionnaire represent all aspects of the construct that is to be measured (Nunnally, 1978). Content validation of an instrument is usually determined via interviews with individuals from the targeted population and/or experts in the field to ensure items and other elements are representative of and relevant to construct being measured (Haynes, Richard, & Kubany,

1995). A more detailed discussion of content validity and its application can be found in Chapter Four.

1.4.2 Criterion-related validity

Criterion validity is the degree to which the instrument correlates with other instruments, usually a 'gold standard' that measures the same variables (Streiner et al., 2015; Heale & Twycross, 2015). Criterion validity consists of two types 1) concurrent validity (which involves correlating the scale with a gold standard) and 2) predictive validity (which involves establishing the predictive power of the measure on some future criterion). A more detailed discussion of criterion validity and its application can be found in Chapter Five.

1.4.3 Construct validity

Construct validity is the extent to which a measurement measures the intended construct (Heale & Twycross, 2015). It is determined by testing hypotheses which were established in advance, such as expected correlations between measures or expected differences in scores between known groups (Terwee et al., 2007). A more detailed discussion of construct validity and its application can be found in Chapter Five.

Despite the relative importance of establishing reliability and validity in questionnaires it is currently unknown whether measures assessing contributing factors to TTP have these above-mentioned psychometric properties.

1.5 Thesis main aim and objectives

To date, research into help-seeking for symptoms of cancer has been hampered by methodological and theoretical issues. This in turn makes it difficult to adequately and systematically assess the decisional and behavioural processes that determine the pathways to diagnosis and treatment (e.g. Andersen et al., 2009; Scott et al., 2013). Consequently, the overall aim of this doctoral research was to develop and validate a questionnaire (the PaTH-Q), based on the theoretical MPT (Scott et al., 2013; Walter et al., 2012), that can be applied with patients who have sought help for potential symptoms of cancer, in order to assess the factors that contributed to their decision to seek help. Specifically, the PaTH-Q examines eight different heuristics involved in symptom appraisal and 'cognitive reasons to consider help-seeking'. This thesis documents the rationale and

theoretical underpinning to the development of the questionnaire and its initial psychometric testing to determine reliability and validity of the new measure.

1.6 Overview of thesis

Chapter Two describes a systematic review to ascertain 1) the psychometric properties of existing measures used to assess psychosocial factors influencing TTP, 2) whether using a measure with sound psychometric properties will result in different reported predictors of TTP, and to 3) help researchers choose suitable measures, as well as to 4) identify any existing instruments or items that could be used in the PaTH-Q. The vast majority of studies were found to be atheoretical and failed to use valid and reliable tools to measure psychosocial factors which may influence help-seeking behaviour.

Chapter Three describes a secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms and decision to seek help by applying the MPT to existing qualitative datasets. The aim of the study was to explore the contributing factors of patients' appraisal of symptoms and decision to seek help that are documented in existing interview transcripts from studies that explored symptom appraisal and help-seeking behaviour in cancer patients. In pursuit of this aim, the study examined whether responses given by interviewees could be classified according to contributing factors (constructs of the CSM) within the appraisal interval of the MPT (Scott et al., 2013; Walter et al., 2012). Classifying the responses according to the contributing factors helped to identify the focus of the PaTH-Q and the ways in which each factor is referred to, which ultimately helped to generate items for the PaTH-Q.

Chapter Four presents the development of an initial item pool and outlines the steps taken to establish content and face validity. Following the findings from the systematic review (Chapter Two) and secondary analysis (Chapter Three), it was decided that items in the PaTH-Q would focus on the heuristics people use to guide symptom interpretation in the 'appraisal' interval of the MPT and 'cognitive reasons to consider help-seeking'. Findings from systematic review and secondary analysis helped inform the generation of items pools in order to create a draft PaTH-Q. Content validity (using an expert panel) and face validity (using a patient panel) were established to determine which elements of the instrument were relevant to and representative of each targeted construct, and allowed refinement, removal and addition of items prior to final questionnaire preparation and administration.

Chapter Five presents the initial psychometric testing of the PaTH-Q via a feasibility study. People who had previously been diagnosed with cancer were asked to complete the PaTH-Q. The psychometric properties of the PaTH-Q were examined by analysing reliability (internal consistency) and convergent validity (which is a subcategory of construct validity).

Chapter Six presents a discussion of the main findings from this thesis. Limitations of the thesis are also discussed, culminating in relevant recommendations for future research and theoretical implications.

Chapter 2 : Measures of psychosocial factors that may influence help-seeking behaviour in cancer: A systematic review of psychometric properties.[4]

2.1 Introduction

This chapter documents a systematic review that aimed to identify how existing studies have measured psychosocial factors affecting actual TTP for [potential] symptoms of cancer. To accomplish this, reference lists of five existing systematic reviews (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999) of patient factors in help-seeking for cancer were searched, and a worldwide systematic literature search was conducted to identify studies that were published since the most recently published systematic review (Mitchell et al., 2007).

2.2 Background

Numerous studies have concluded that TTP may be influenced by a range of psychosocial factors. However five systematic reviews that examined help-seeking for symptoms of cancer have yielded mixed findings concerning which psychosocial factors influence TTP and whether they increase or decrease TTP (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999). For example, findings from the systematic review published by Macdonald et al. (2004) found that studies pertaining to symptom awareness among individuals with upper gastrointestinal (GI) cancer was associated with shorter TTP in three studies (Delaney, 1998; Gullo, Tomassetti, Migliori, Casadei, & Marrano, 2001; Ojala, Sorri, Jokinen, & Kairaluoma, 1982) and with longer TTP in six studies (Arvanitakis et al., 1992; Ibingira, 2001; Mikulin & Hardcastle, 1987; Nagao & Takahashi, 1979; Porta, Gallen, Belloc, & Malats, 1996; Rothwell, Feehan, Reid, Walsh, & Hennessy, 1997). Another psychosocial factor which has shown to have an inconclusive impact on TTP are social networks (as defined by a network of friends, colleagues, and other personal contacts). In lower GI cancer, social networks were identified to reduce TTP in five studies (Camilleri-Brennan & Steele, 1999; Holliday & Hardcastle, 1979; MacArthur & Smith, 1984; Roncoroni et al., 1999; Sladden, Thomson, & Lombard, 1999), whereas it was not regarded as important in two studies (Macadam, 1979; Samet, Hunt, Lerchen, & Goodwin, 1988). Fear of lower GI symptoms suggestive of cancer

[4] A version of this chapter has been accepted for publication. See **Appendix 1** for a copy of the pre-publication proof

led to longer TTP in four studies (Byles, Redman, Hennrikus, Sansonfisher, & Dickinson, 1992; de Nooijer et al., 2001a; de Nooijer et al., 2001b; Prohaska et al., 1990), whereas it was linked to shorter TTP in five studies (de Nooijer et al., 2001a; de Nooijer et al., 2001b; Dent et al., 1990; Hackett, Cassem, & Raker, 1973; Sladden et al., 1999). Similar findings concerning the impact of emotions have been found by Balasooriya-Smeekens et al. (2015) who noted that the impact of emotions on TTP was mixed. It is hypothesised that mixed findings may have occurred because different studies have used different ways of defining and measuring psychosocial factors, including the use of measures without proven reliability or validity.

Although there has been a focus on the design and validation of measures examining factors influencing *hypothetical* help-seeking behaviour, for example as evidenced by studies published by Stubbings et al. (2009) or by Simon et al. (2012), there is sparse information about whether quantitative measures of psychosocial factors affecting TTP are reliable or valid. This makes it difficult to guide the selection of measures to robustly assess the key decisional and behavioural processes that affect the pathways to healthcare use, or to select measures for use in the evaluation of interventions aiming to promote timely presentation (Scott & Walter, 2010). The Aarhus Statement on improving methodological approaches in early diagnosis research (Weller et al., 2012) suggested the need for valid and reliable measures. Furthermore, Simon et al. (2012) suggested that research into help-seeking behaviour could be improved by use of valid and reliable measurements that encompass items on beliefs potentially associated with help-seeking behaviour. To establish the reliability and validity of a measure a number of criteria need to be determined. A brief overview was documented in Chapter One and a detailed overview of the indicators of a robust measure and its importance can be found in Chapter Four and Chapter Five respectively.

Furthermore, it can be argued that in help-seeking research the absence of theoretically guided studies has led to psychosocial factors being chosen unsystematically. This is problematic because it results in a large list of factors which can be impossible to measure in a single study (Scott & Walter, 2010). Without theoretical underpinning researchers are unable to adequately determine which factors are most important, how and when in the diagnostic pathway factors have an effect, or if some factors have more than one effect (Scott & Walter, 2010).

2.3 Aims and Objectives

The primary aim of this systematic review was to investigate the psychometric properties of current measures used to assess psychosocial factors affecting TTP. The secondary aim was to use this information to assess whether using a robust measure (rather than one with no proven validity or reliability) results in different reported predictors of TTP. Doing so would serve two functions: 1) to help researchers choose suitable measures and 2) to identify areas in which new psychometrically robust measures are needed.

2.4 Methods

2.4.1 Data Search

Two approaches to searching the data were used. Firstly, reference lists of five existing systematic reviews (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999) with respect to patient factors in help-seeking were searched as they a) documented a comprehensive review of the world literature from 1966 to 2003; b) encompassed a range of cancers (upper and lower GI cancers, skin cancers, head and neck cancers, urological cancers, gynaecological cancers, lung cancer, brain tumours, haematological malignancies, sarcomas and breast cancer), and c) used both quantitative and qualitative methods. Secondly, a worldwide systematic literature search was conducted to identify studies that were published since the most recently published systematic review (Mitchell et al., 2007).

2.4.2 Existing Systematic Reviews Search

The reference lists of the five existing systematic reviews (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999) were searched (**Table 2**) to identify studies that have examined how psychosocial factors affect actual TTP for [potential] symptoms of cancer.

Table 2 Existing systematic reviews that have explored factors influencing help-seeking behaviour

Author (Year)	Title	Cancer Type(s)	Databases searched
Mitchell et al. (2007)	Influences on pre-hospital delay in the diagnosis of colorectal cancer: a systematic review	Colorectal	Bibliographic databases: Medline, EMBASE, CINAHL, PsycINFO, ISI Science Citation Index, ISI Social Sciences Citation Index, International Bibliography of the Social Sciences Proceedings First and Web of Science Proceedings Cochrane Collaborative Review Groups: The Colorectal Cancer, Gynaecological Cancer, Lung Cancer, Prostatic Diseases and Urologic Cancers, Haematological Malignancies, Oral Health, Skin, Upper Gastrointestinal and Pancreatic Diseases, Effective Practice and Organisation of Care and Consumers and Communication Collaborative Review Groups were contacted and asked to provide details of potentially relevant studies that they had identified Grant awarding bodies: National Research Register, Department of Health Research Findings electronic Register (ReFeR), Medical Research Council, Cancer Research UK and the Chief Scientist Office of the Scottish Executive Health Department National and international contacts: Database of almost 300 UK contacts, containing Scottish and English health authorities, cancer networks and cancer leads, with a

Author (Year)	Title	Cancer Type(s)	Databases searched
			particular interest in cancer was established. List of international contacts was also compiled, including similar organisations in North America, Europe, Australia and New Zealand Other sources: Requests made to authors active in the field for studies-in-progress and unpublished work. Citations in literature reviews and articles obtained were also reviewed along with references provided by colleagues.
Macdonald et al. (2006)	Systematic review of factors influencing patient and practitioner delay in diagnosis of upper GI	Upper GI	Bibliographic databases: Medline, EMBASE, CINAHL, PsycINFO, ISI Science Citation Index, ISI Social Sciences Citation Index, International Bibliography of the Social Sciences Proceedings First and Web of Science Proceedings Cochrane Collaborative Review Groups: The Colorectal Cancer, Gynaecological Cancer, Lung Cancer, Prostatic Diseases and Urologic Cancers, Haematological Malignancies, Oral Health, Skin, Upper Gastrointestinal and Pancreatic Diseases, Effective Practice and Organisation of Care and Consumers and Communication Collaborative Review Groups were contacted and asked to provide details of potentially relevant studies that they had identified Grant awarding bodies: National Research Register, Department of Health Research Findings electronic Register

Author (Year)	Title	Cancer Type(s)	Databases searched
			(ReFeR), Medical Research Council, Cancer Research UK and the Chief Scientist Office of the Scottish Executive Health Department <u>National and international contacts:</u> Database of almost 300 UK contacts, containing Scottish and English health authorities, cancer networks and cancer leads, with a particular interest in cancer was established. List of international contacts was also compiled, including similar organisations in North America, Europe, Australia and New Zealand <u>Other sources:</u> Requests made authors active in the field for studies-in-progress and unpublished work. Citations in literature reviews and articles obtained were also reviewed along with references provided by colleagues.
Macdonald et al. (2004)	Factors influencing patient and primary care delay in the diagnosis of cancer: a database of existing research and its implications for future practice	Lung, upper GI, lower GI, gynaecological, urological, haematological, skin, head and neck, brain/ central nervous system and sarcomas	<u>Bibliographic databases:</u> Medline, EMBASE, CINAHL, PsycINFO, ISI Science Citation Index, ISI Social Sciences Citation Index, International Bibliography of the Social Sciences Proceedings First and Web of Science Proceedings <u>Cochrane Collaborative Review Groups:</u> The Colorectal Cancer, Gynaecological Cancer, Lung Cancer, Prostatic Diseases and Urologic Cancers, Haematological Malignancies, Oral Health, Skin, Upper Gastrointestinal and Pancreatic Diseases, Effective

Author (Year)	Title	Cancer Type(s)	Databases searched
			Practice and Organisation of Care and Consumers and Communication Collaborative Review Groups were contacted and asked to provide details of potentially relevant studies that they had identified Grant awarding bodies: National Research Register, Department of Health Research Findings electronic Register (ReFeR), Medical Research Council, Cancer Research UK and the Chief Scientist Office of the Scottish Executive Health Department National and international contacts: Database of almost 300 UK contacts, containing Scottish and English health authorities, cancer networks and cancer leads, with a particular interest in cancer was established. List of international contacts was also compiled, including similar organisations in North America, Europe, Australia and New Zealand Other sources: Requests made authors active in the field for studies-in-progress and unpublished work. Citations in literature reviews and articles obtained were also reviewed along with references provided by colleagues.
Ramirez et al. (1999)	Factors predicting delayed presentation of symptomatic breast cancer: a systematic review	Breast	Bibliographic databases: Medline, Cancer CD (Combination of cancer relevant citations including CancerLit, Embase and the Yearbook of Oncology), PsycINFO, CINAHL, Sociological

Author (Year)	Title	Cancer Type(s)	Databases searched
			Abstracts, ISI Science Citation Index Other sources: Manual searches of the bibliographies of original reports and major (non-systematic) review articles. Unpublished data through contacting experts in the field of breast cancer.
Richards et al., 1999	Influence of delay on survival in patients with breast cancer: a systematic review	Breast	Bibliographic databases: Medline, Cancer CD (Combination of cancer relevant citations including CancerLit, Embase and the Yearbook of Oncology), PsychINFO, CINAHL, Sociological Abstracts, ISI Science Citation Index Other sources: Manual searches of the bibliographies of original reports and major (non-systematic) review articles. Unpublished data through contacting experts in the field of breast cancer.

2.4.3 Updated Literature Search

Databases were systematically searched from January 2004 to May 2014. References were searched from 2004 onwards given that the systematic reviews published to date have documented a comprehensive review of the world literature from 1966 to November 2003.

The systematic search was performed in Medline, Embase, CINAHL, PsycINFO and Web of Science as these databases contain medical, psychological and social scientific papers that could all be relevant to the issue of psychosocial factors affecting actual TTP for [potential] symptoms of cancer.

2.4.4 Search strategy

The search strategy for the search was originally based on the search strategy used by Macdonald et al. (2004) and adapted for the purpose of this review in collaboration with an

information specialist at the Dental Institute and Physiotherapy (King's College London). However, after initially performing the search in EMBASE, Medline and PsycInfo, the search yielded in excess of 100 000 references. Consequently, the Medical School Librarian at the University of Cambridge, Isla Kuhn (IK), was consulted to help with the development of a revised search strategy, and the relevant MeSH terms and synonyms (e.g. for cancer and help-seeking) were identified and finalised.

Search terms focused on four main themes: psychosocial factors, help-seeking, cancer and symptoms. An overview of the search terms used for the different databases can be found in **Appendix 2** to **Appendix 6**.

2.4.4.1 Definitions of search terms

2.4.4.1.1 Psychosocial Factors

Given the large number of possible psychosocial factors, a clear definition for the relevant psychosocial factors was formulated at the outset of the review. This was based on the methodology applied by Ramirez et al. (1999) who formulated clear hypotheses for each factor at the outset of their review on factors predicting delayed presentation of symptomatic breast cancer, given the large number of possible factors and their likely interactions. According to the authors' classification, psychosocial factors encompass "emotional, cognitive, and behavioural responses of the patient to the discovery of a breast symptom, and social influences, psychiatric history, and previous medical help-seeking" (p. 1128) (Ramirez et al., 1999). In order to generate and identify a list of search terms based on Ramirez et al.'s (1999) criteria for psychosocial factors, search terms were generated through psychosocial factors identified in the five existing systematic reviews (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999). Search terms were also based on the findings of a qualitative synthesis conducted by Smith, Pope and Botha (2005) that investigated patients' help-seeking experiences and delay in cancer presentation. Further to this, agreement on included psychosocial factors was reached in collaboration with the researcher's (SK) supervisors (SS, FW) and the librarian (IK).

2.4.4.1.2 Help-seeking

Synonyms for help-seeking behaviour were obtained through existing literature on the topic and agreed upon in consultation with the researcher's supervisors and the librarian.

Care was taken to ensure that terms representing all aspects of help-seeking behaviour were included, in line with the definition of help-seeking behaviour by Scott and Walter (2010) who noted that "Help-seeking behaviour involves processes of symptom perception, interpretation, appraisal and decision-making in addition to having the ability and motivation to enforce the decision by visiting a HCP" (p. 531). Terms such as 'professional referral' and 'health care service' were also included because they were commonly used MeSH terms closely related to the topic of help-seeking.

2.4.4.1.3 Cancer

All types of cancer were included in the review, as it was important to explore how psychosocial factors affect actual TTP for all [potential] symptoms of cancer and to be able to compare findings across cancer types. The most commonly used terms (free text and MeSH terms) for cancer were included and confirmed with SS, FW and IK.

2.4.5 Inclusion and exclusion criteria

Original research papers published in peer-reviewed journals, which examined how psychosocial factors affect actual TTP for [potential] symptoms of cancer (all types), were included. Manuscripts were excluded if they were not peer-reviewed, abstracts (presentations at conferences or meetings), reviews, or studies on screening, or set among asymptomatic individuals. Papers on screening were excluded because the scope of the review was to measure first-time presentation to a healthcare professional with [potential] symptoms. Qualitative studies, even when data were later quantified, were excluded because the purpose of this review was to examine how existing studies have measured psychosocial factors influencing TTP in a quantitative manner (e.g. through the use of structured interviews, medical records or (self-administered) questionnaires).

See **Box 1** for the final inclusion and exclusion criteria.

Box 1 Inclusion and exclusion criteria

Include	*Exclude*
• Original research papers published in peer-reviewed journals • Quantitative and mixed-method studies • Study examined psychosocial factor(s) (emotional, cognitive and behavioural responses of the patient to the discovery of a symptom, social support/influences) specific to symptom appraisal, help-seeking or time to presentation • All papers published from 1966 until May 2014 • Any language • Any age or gender (participants) • Studies on cancer (all types) and/or symptoms potentially indicative of cancer	• Unpublished manuscripts • Non peer-reviewed papers • Abstracts (presented at meetings) • Studies on diseases other than cancer • Studies with participants previously diagnosed with the same type of cancer • Studies on screening

2.4.6 Study selection

Titles and abstracts of all the papers identified through the search strategy were assessed using the inclusion and exclusion criteria (see **Box 1**). Full text papers of any potentially relevant titles and abstracts were then obtained. If the full text paper was not available online a hard copy was requested from the library for further assessment. A rigorous approach was applied by which all full text papers were assessed by the researcher against the inclusion and exclusion criteria. This was then validated by the researcher's supervisors (SS and FW). Agreement on inclusion was reached through discussion of the papers with all three reviewers. The references of all included papers were also screened for any potential relevant studies.

2.4.7 Data extraction

Data from all included papers were extracted using a data extraction form that was specifically developed for this review, and based on data extraction forms developed by Andrew Webster (AW) (Walter et al., 2012) and Juliet Usher-Smith (JUS) (Usher-Smith, Silarova, Schuit, Moons, & Griffin, 2015). Data were double extracted for each paper by either SS or FW to ensure rigor. The three reviewers reached consensus about extracted data through discussions. Extracted data included the following:

1. which psychosocial factors were measured
2. study and participant characteristics
3. measurement details
4. how factors were measured
5. whether a definition for appraisal, help-seeking and/or TTP was provided
6. items/questions used
7. details on validity and reliability
8. relationship between psychosocial variables and TTP (when inferential statistics were used).

See **Appendix 7** for the data extraction form. Data relating to point 8 were extracted separately following peer review advice.

2.4.8 Analysis

A descriptive narrative approach was chosen to synthesise the data, because the data extraction (process) revealed a lack of homogenous study methods. For instance:

1. studies used a variety of questionnaires to measure different psychosocial factors. For instance, Terwee et al. (2007) noted that combining results of different studies on a measurement property of an instrument is only possible when the studies are sufficiently similar with regard to study population and setting;
2. there was insufficient detail about whether the measures used to determine the impact of psychosocial factors on TTP were valid and/or reliable;
3. details about whether psychosocial factors were associated with TTP was frequently not available.

Thus, it was not possible to review the data using a meta-analysis. Nevertheless, it is believed that a descriptive narrative approach is of value in this review, because it enabled the measurement information to be to assessed, compared and contrasted.

A quality assessment was not carried out as part of this review. It is acknowledged that quality criteria to determine the measurements properties of measures exist, such as the quality criteria that were proposed for measurement properties of health status questionnaires by Terwee et al. (2007). However, similar to the rationale of not performing a meta-analysis, upon extracting the data for this study it was noted that there was inconsistent reporting of the reliability and validity of the questionnaires used. For

example, authors did not report how the questionnaire was developed or the validation process, or some authors reported validity but not reliability. Further, the researcher did not want to exclude any studies based on their quality as one of the aims was to investigate the psychometric properties of current measures used to assess psychosocial factors affecting TTP. Consequently, it is believed that doing so actually represents a quality assessment in itself.

2.5 Results

From the initial total of 20 953 unique abstracts identified via the systematic search, 36 papers were included in the review (see **Figure 3** for the PRISMA flow diagram of the in- and exclusion process and reasons for exclusion).

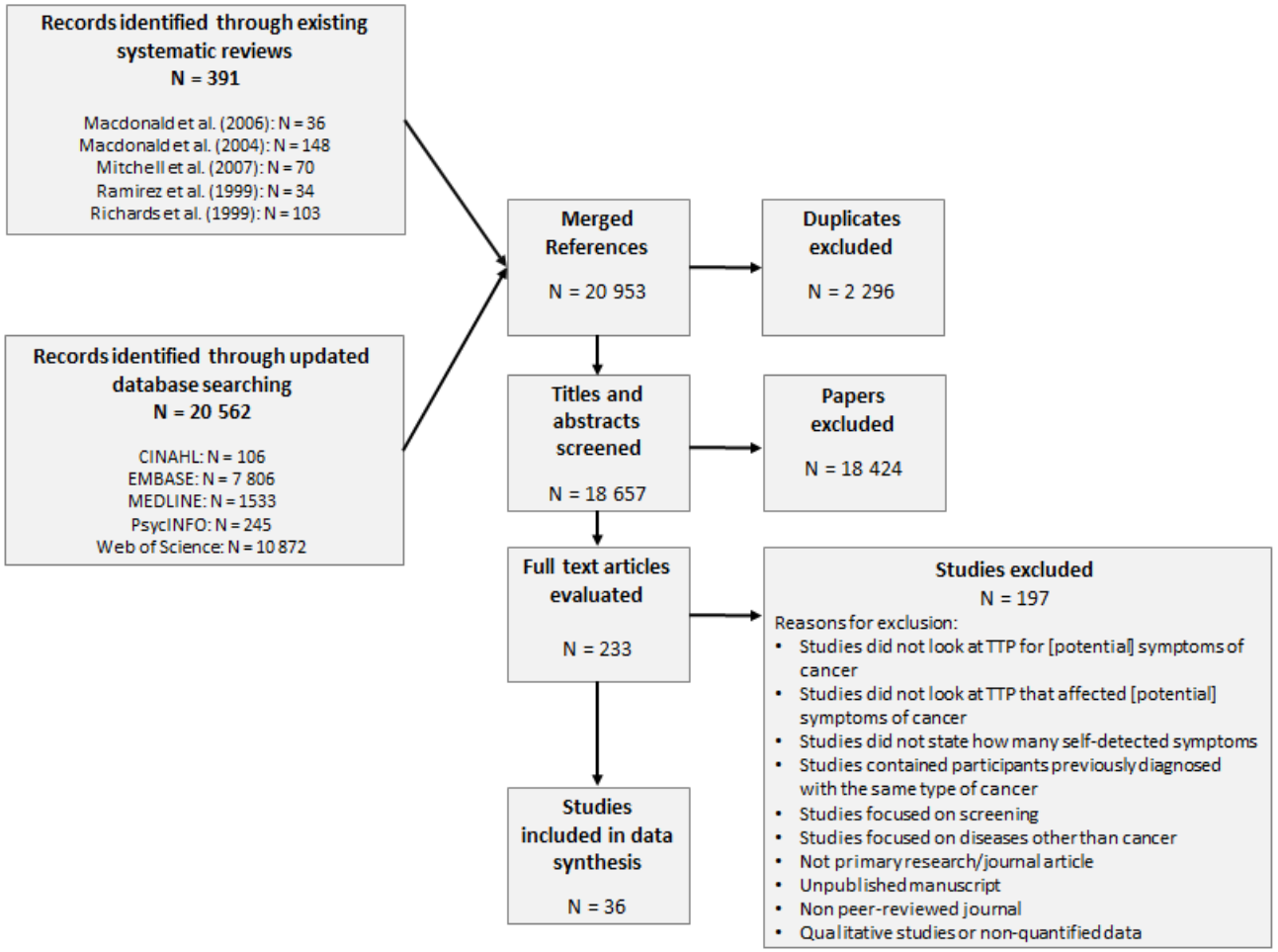

Figure 3 PRISMA flow diagram

2.5.1 Study and Participant Characteristics

Details of the 36 included papers can be found in **Table 3**. The sample size of the studies ranged from 37 (Bowen & Rayner, 2002) to 1085 (Courtney et al., 2012) participants. The mean age ranged from 31 years (Bosl et al., 1981) to 88.8 years (Smith et al., 2009). The majority of studies were set in North America (n = 12) (Alam, 2011; Andersen et al., 1995; Bosl et al., 1981; Cochran, Hackett, & Berek, 1986; Friedman et al., 2006; Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Oliveria et al., 1999; Prohaska, Funch, & Blesch, 1990, 1990; Reifenstein, 2007; Ristvedt & Trinkaus, 2005; Smith & Anderson, 1985; Unger-Saldana, Pelaez-Ballestas, & Infante-Castaneda, 2012) and the United Kingdom (n = 6) (Bowen & Rayner, 2002; Cameron & Hinton, 1968; Doherty & MacKie, 1986; Greer, 1974; Scott, McGurk, & Grunfeld, 2008; Smith et al., 2009). The remainder of the studies were conducted in a range of countries, including Europe (n = 14) (Adrien, Bertolus, Gambotti, Mallet, & Baujat, 2014; Brochez, Verhaeghe, Bleyen, & Naeyaert, 2001; Forghieri et al., 2010; Kakagia et al., 2013; Mansson, Anderson, & Colleen, 1993; O'Mahony & Hegarty, 2009; O'Mahony, McCarthy, Corcoran, & Hegarty, 2013; Panzarella et al., 2014; Popescu, Turcu, Ghervase, Forsea, & Giurcaneanu, 2013; Richard, Grob, Avril, Delaunay, Gouvernet, Wolkenstein, et al., 2000; Risberg, Sorbye, Norum, & Wist, 1996; Schmid-Wendtner, Baumert, Stange, & Volkenandt, 2002; Skeppner, Andersson, Johansson, & Windahl, 2012; Tromp, Brouha, Hordijk, Winnubst, & de Leeuw, 2005), Australasia (n = 3) (Courtney et al., 2012; Hashim et al., 2010; Li et al., 2012) and India (n = 1) (Kumar et al., 2001).

The majority of studies (n = 9) were conducted with individuals with breast cancer (Cameron & Hinton, 1968; Friedman et al., 2006; Greer, 1974; Gullatte et al., 2010; Li et al., 2012; O'Mahony & Hegarty, 2009; O'Mahony et al., 2013; Reifenstein, 2007; Unger-Saldana et al., 2012),eight studies reported data from various types of skin cancer (melanomas and cutaneous squamous cell) (Brochez et al., 2001; Doherty & MacKie, 1986; Forghieri et al., 2010; Kakagia et al., 2013; Oliveria et al., 1999; Popescu et al., 2013; Richard, et al., 2000; Schmid-Wendtner et al., 2002), four studies investigated colorectal cancer (Courtney et al., 2012; Hashim et al., 2010; Prohaska, et al., 1990; Ristvedt & Trinkaus, 2005), whereas five studies looked at head and neck cancer (Adrien et al., 2014; Tromp et al., 2005) or oral cancer (Kumar et al., 2001; Panzarella et al., 2014; Scott et al., 2008). Two studies each focused on endometrial (Cochran et al., 1986; Smith & Anderson, 1985) and lung (Bowen & Rayner, 2002; Smith et al., 2009) cancer, whereas there was a single report each concerning bladder (Mansson et al., 1993), germ cell testicular (Bosl et al., 1981), penile

(Skeppner et al., 2012) and non-melanoma skin cancer (Alam, 2011). One study (Risberg et al., 1996) reported findings from a variety of cancer types and one study investigated a range of gynaecological malignancies (Andersen et al., 1995).

As most studies reported symptoms of breast cancer, their samples were exclusively female (n = 1868 in total across nine studies); studies on other cancer types included both males and females, except for studies on endometrial cancer (n = 117 across two studies), gynaecological malignancies (n = 34), germ cell testicular cancer (n = 335) and penile (n = 59) cancer.

2.5.2 Methodology of studies

Most studies (n = 34), with the exception of two (Courtney et al., 2012; Smith & Anderson, 1985) provided a definition for appraisal, help-seeking or TTP. Psychological factors affecting actual TTP for [potential] symptoms of cancer were primarily measured via self-administered questionnaires (n = 20) (Adrien et al., 2014; Alam, 2011; Bowen & Rayner, 2002; Cameron & Hinton, 1968; Courtney et al., 2012; Forghieri et al., 2010; Friedman et al., 2006; Gullatte et al., 2010; Hashim et al., 2010; Kumar et al., 2001; Mansson et al., 1993; O'Mahony & Hegarty, 2009; O'Mahony et al., 2013; Popescu et al., 2013; Reifenstein, 2007; Risberg et al., 1996; Ristvedt & Trinkaus, 2005; Scott et al., 2008; Smith & Anderson, 1985; Tromp et al., 2005) and interviewer adminstered questionnaires (n = 14), which included structured interviews and physician administered interviews (Andersen et al., 1995; Brochez et al., 2001; Doherty & MacKie, 1986; Greer, 1974; Kakagia et al., 2013; Li et al., 2012; Oliveria et al., 1999; Panzarella et al., 2014; Prohaska et al., 1990; Richard et al., 2000; Schmid-Wendtner et al., 2002; Skeppner et al., 2012; Smith et al., 2009; Unger-Saldana et al., 2012). One study used medical records (Bosl et al., 1981) and one used a combination of structured interviews and questionnaires (Cochran et al., 1986).

The 36 papers documented 108 measures in total: most (78%; n = 84) were newly developed for that specific study while about a quarter (n = 24) used existing scales (16 of which were modified for the study). Where existing scales were used, most (92%; n = 22) had some evidence of reliability (mainly internal reliability) or validity or both. The new measures rarely documented psychometric properties: 7% (n = 5) demonstrated internal reliability; 11% (n = 9) demonstrated test-retest reliability; 15% (n = 12) demonstrated face validity; 12% (n = 10) demonstrated content validity; 4% (n = 3) demonstrated construct validity. None of the new measures were tested for criterion validity.

Eleven studies (Andersen et al., 1995; Friedman et al., 2006; Hashim et al., 2010; Kumar et al., 2001; Li et al., 2012; O'Mahony & Hegarty, 2009; O'Mahony et al., 2013; Reifenstein, 2007; Ristvedt & Trinkaus, 2005; Scott et al., 2008; Unger-Saldana et al., 2012) stated that theoretical models and/or literature reviews were used to inform the study design, but it was not always clear as to whether theoretical models were used in the design of the new questionnaires.

Table 3 Patient Characteristics across the 36 included studies

Authors (Year)	Country	Sample (n)	Cancer Type	Definition for appraisal, help-seeking and/or TTP given	Aims To identify…
Adrien et al. (2014)	France	668	Head and neck	✓	Healthcare inequalities and socio-economic factors influencing late-stage diagnosis.
Alam (2011)	USA	860	Skin	✓	Reasons for delayed presentation for diagnosis and treatment.
Andersen et al. (1995)	USA	34	Gynaecological malignancies	✓	Inferences and decisions an individual makes as time passes from symptom detection to consulting with a HCP.
Bosl et al. (1981)	USA	335	Germ-cell testicular	✓	Extent and causes of diagnostic delay, and impact of delay on disease stage.
Bowen and Rayner (2002)	UK	37	Lung	✓	Time between symptom occurrence and presentation to a GP.
Brochez et al. (2001)	Belgium	130	Skin	✓	Diagnostic pathway, patient and physician delay and factors related to it.
Cameron and Hinton (1968)	UK	83	Breast	✓	If certain aspects of the tumour, patients' personalities or social background were linked to consultation delay.
Cochran et al. (1986)	USA	37	Endometrial	✓	Physical, interpersonal, and psychological factors associated with delay to identify barriers to early treatment.
Courtney et al. (2012)	Australia	1085	Colorectal	–	Proportion ever experiencing a symptom in their lifetime and the non-consultation rate for each primary symptom of cancer.
Doherty and MacKie (1986)	UK	125	Skin	✓	Any evidence of inappropriate delay in receiving surgical treatment for a new or changing pigmented lesion.
Forghieri et al. (2010)	Italy	120	Skin	✓	If attitude towards illness of those attending a melanoma screening day differs from those diagnosed via the usual clinical pathway.
Friedman et al. (2006)	USA	99	Breast	✓	Demographic, medical and psychosocial factors related to delay

Authors (Year)	Country	Sample (n)	Cancer Type	Definition for appraisal, help-seeking and/or TTP given	Aims To identify…
Greer (1974)	UK	157	Breast	✓	Delay in seeking and obtaining treatment for breast lumps.
Gullatte et al. (2010)	USA	124	Breast	✓	Relationship between religiosity, spirituality, breast cancer fatalism, disclosure of symptoms, and marital status, and time to seek medical care and breast cancer stage
Hashim et al. (2010)	Malaysia	80	Colorectal	✓	Prevalence of consultation delay and identifying associated factors
Kakagia et al. (2013)	Greece	513	Skin	✓	Risk factors of patient-related delayed presentation.
Kumar et al. (2001)	India	52	Oral	✓	Psychosocial factors related to delay and the relationship between delay and cancer stage.
Li et al. (2012)	China	425	Breast	✓	Determinants of patient delay in indigenous Chinese women.
Mansson et al. (1993)	Sweden	203	Bladder	✓	Factors influencing patient's delay and doctor's delay.
O'Mahony and Hegarty (2009)	Ireland	99	Breast	✓	Extent of delay and factors influencing help-seeking.
O'Mahony et al. (2013)	Ireland	449	Breast	✓	Help seeking behaviour and associated factors on self-discovery of a breast symptom as depicted in a conceptual framework.
Oliveria et al. (1999)	USA	255	Skin	✓	Relationship between patients' knowledge and awareness of melanoma signs and symptoms and delay for suspicious lesions.
Panzarella et al. (2014)	Italy	156	Oral	✓	Variables linked to delay, mainly cognitive and psychological factors.
Popescu et al. (2013)	Romania	122	Skin	✓	Gender differences in practices and attitudes related to early detection.
Prohaska et al. (1990)	USA	254	Colorectal	✓	Symptom perceptions and illness behaviours prior to diagnosis to determine age patterns and their effect on self-care activities.

Authors (Year)	Country	Sample (n)	Cancer Type	Definition for appraisal, help-seeking and/or TTP given	Aims To identify…
Reifenstein (2007)	USA	48	Breast	✓	Care-seeking behaviours of African American women so interventions for breast cancer symptoms can be developed and tested in the future.
Richard et al., 2000	France	590	Skin	✓	Patient- and doctor-related components in the delay before diagnosis and the prognosis of cutaneous melanoma.
Risberg et al. (1996)	Norway	252	Various	✓	Delays involved in diagnosis and treatment and the possible psychological distress associated to the different delay periods.
Ristvedt and Trinkaus (2005)	USA	69	Rectal	✓	Role of negative affective traits in delayed help seeking for symptoms of rectal cancer.
Schmid-Wendtner et al. (2002)	Germany	233	Skin	✓	Extent and consequence of patient and professional delay in diagnosis and treatment.
Scott et al. (2008)	UK	80	Oral	✓	Understanding of patient delay to inform the development of interventions to encourage early presentation of oral cancer.
Skeppner et al. (2012)	Sweden	59	Penile	✓	Initial symptoms and factors linked to patients' and doctors' delay.
Smith and Anderson (1985)	USA	80	Endometrial	–	Characteristics of symptoms associated with stage and other extent of disease factors at diagnosis.
Smith et al. (2009)	UK	360	Lung	✓	Factors associated with the time taken to consult, with a focus on those from rural and socially deprived areas.
Tromp et al. (2005)	Holland	264	Head and neck	✓	Relationship between relevant health behaviours and health value and control beliefs, as well as psychological distress.
Unger-Saldana	Mexico	384	Breast	✓	Time intervals from possible cancer detection to the beginning of

Authors (Year)	Country	Sample (n)	Cancer Type	Definition for appraisal, help-seeking and/or TTP given	Aims To identify…
et al. (2012)					treatment and the factors predicting prolongation of these intervals.

2.5.3 Psychosocial Factors

Eleven broad categories of psychosocial factors were measured in the included studies.

1. Reasons for delay
2. Reasons for seeking help
3. Knowledge
4. Perceived risk
5. Access to Healthcare
6. Emotional response to symptoms
7. Symptom interpretation
8. Social factors[5]
9. Coping methods[6]
10. Spirituality and Religiousness
11. Health values

These eleven broad categories of psychosocial factors are outlined below. Measures showing evidence of reliability and validity are discussed in more detail. The findings of the studies (focusing on the relationship between each psychosocial factor and TTP) are then presented in relation to the studies' reported psychometric properties.

2.5.3.1 Reasons for delay

i. Robustness of measures

Seventeen studies explored how reasons for delay affected actual TTP for [potential] symptoms of cancer (Alam, 2011; Bosl et al., 1981; Courtney et al., 2012; Doherty & MacKie, 1986; Friedman et al., 2006; Kakagia et al., 2013; Li et al., 2012; O'Mahony & Hegarty, 2009; Popescu et al., 2013; Prohaska et al., 1990; Reifenstein, 2007; Richard et al., 2000; Schmid-Wendtner et al., 2002; Scott et al., 2008; Skeppner et al., 2012; Smith & Anderson, 1985; Unger-Saldana et al., 2012). **Table 4** documents the psychometric properties and TTP for 'Reasons for Delay', whereas **Table 5** documents the measure/items used for 'Reasons for Delay'.

[5] 'Social factors' encompasses elements such as failure to disclose symptoms to significant others, lack of support from family or friends, perceptions of significant others in an individual's life and competing priorities, which can affect help-seeking behaviour (Scott & Walter, 2010).

[6] 'Coping Methods' refers to coping procedures as a means of danger control (for example by using self-medication or symptom monitoring) or fear control (for example by hoping that the problem will go away or denial) (Scott et al., 2013).

Only three studies (Reifenstein, 2007; Scott et al., 2008; Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Reifenstein (2007) used an adapted 12 item version (Lauver, 1994) of “Melnyk’s Barrier Scale” (Melnyk, 1990) to assess barriers. Items are scored from 1 (‘not at all’) to 4 (‘greatly’). The full scale was not provided, but Reifenstein (2007) noted that barriers were measured by the extent to which perceived barriers (e.g. 'the high cost of transportation and/or parking' or 'the long wait between making an appointment and the actual appointment') influenced help-seeking. Internal consistency for the scale was reported as Cronbach’s $\alpha = 0.73$ in Reifenstein’s study (2007) and Cronbach’s $\alpha = 0.70$ in the study conducted by Lauver (1994).

Scott et al. (2008) determined the presence of competing events in participants’ lives using a modified version of the “Social Readjustment Scale” (Holmes & Rahe, 1967). No details on reliability or validity were reported by Scott et al. (2008), but Gerst, Grant, Yager, and Sweetwood (1978) had previously examined the reliability of the “Social Readjustment Scale” in groups of psychiatric outpatients and non-patients (male employees at a hospital and university campus) during three sampling periods over two years, finding that total rank ordering remained consistent for psychiatric outpatients ($r = 0.91$ to $r = 0.70$) and non-patients ($r = 0.96$ to $r = 0.89$) over the sampling periods.

Unger-Saldana et al. (2012) examined ‘patient’s perceived reason for patient delay’ by assessing a range of factors such as lack of financial resources, embarrassment or difficulty to miss work. Participants were asked 'Why did you not seek medical care sooner?' and read nine options (e.g. ‘Because you thought the problem would disappear on its own?’) to which they were asked to respond ‘yes’ or ‘no’ to each. Internal consistency for this dimension was reported as good, with Cronbach’s $\alpha = 0.85$. The specific test-retest correlation for this specific scale was not indicated, but the authors noted that test-retest correlations ranged from poor ($r < 0.4$) to good ($r > 0.75$) for the whole questionnaire. Tests of convergent validity showed that items within this dimension correlated with each other ($r = 0.2$ to $r = 0.64$). Items belonging to different dimensions were either poorly or not correlated with each other, therefore indicating divergent validity. Face and content validity of the entire questionnaire was investigated in the questionnaire development process using evaluation from a multidisciplinary team.

ii. Relationship with TTP

'Reasons for delay' were generally associated with longer TTP (Friedman et al., 2006; Kakagia et al.; 2013; Li et al., 2012; O'Mahony & Hegarty, 2009; Scott et al., 2008). However, not all measured barriers were found to be associated with longer TTP. For example, findings by Friedman et al. (2006), whose barrier items identified 'cancer worry', 'appointment trouble', 'cost', 'treatment worry', 'fear of breast loss', 'can't get off work and 'rather not think about it', showed that only being 'more likely to identify cost' and 'rather not to think about it' was associated with longer TTP. Findings by Kakagia et al. (2013) showed that all the variables other than 'fear of diagnosis' were assocaited with longer TTP. For one study (Prohaska et al., 1990) only one out of eight barriers was assocaited with shorter TTP. There was no significant relationship between 'reasons for delay' and TTP in two studies (Reifenstein, 2007; Smith & Anderson, 1985). None of these studies used measures with evidence of validity and only two studies showed evidence of reliability (Reifenstein, 2007; Scott et al., 2008).

Table 4 Psychometric Properties and TTP for 'Reasons for Delay'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Subjective patient-specific factors	Alam (2011)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Reasons for delay	Bosl et al. (1981)	Medical Records	–	–	–	–	–	–	–	–
Reason for delay	Courtney et al. (2012)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Reasons for delay	Doherty and MacKie (1986)	Interviewer	New	–	–	–	–	–	–	–
Barriers to seeking a medical consultation	Friedman et al. (2006)	Self-administered questionnaire	New	–	–	–	–	–	–	= ↑[7]
Reasons delaying presentation	Kakagia et al. (2013)	Interviewer	New	–	–	–	–	–	–	= ↑[8]

↑ = longer TTP; ↓ = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

[7] 'More likely to identify cost' ($p < 0.001$) and 'not wanting to think about it' associated with longer TTP in between group comparisons. Other barriers ('hard to get an appointment', 'hard to get off work', 'worried it might be cancer', 'worried about cancer treatment', 'worried that I might lose my breast' and 'too long a wait at the clinic') not associated with TTP in between group comparisons.

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Competing life priorities	Li et al. (2012)	Interviewer	New	–	–	–	–	–	–	↑
Factors which made it more difficult to visit GP	O'Mahony and Hegarty (2009)	Self-administered questionnaire	Existing (Modified for study) (Meechan, Collins, & Petrie, 2002)	–	–	–	–	–	–	↑[9]
Barriers to seeking help	Popescu et al. (2013)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Barriers to seeking medical care	Prohaska et al. (1990)	Interviewer	New	–	–	–	–	–	–	= ↓[10]
Barriers	Reifenstein (2007)	Self-administered questionnaire	Existing (Melnyk, 1990; adapted by Lauver, 1994)	✓	–	–	–	–	–	=
Reasons for	Richard et	Interviewer	New	–	–	–	–	–	–	–

[8] 'Embarrassment' (p = 0.003; OR = 1.33; CI = 0.8–2.3), 'fear of investigations and management' (p = <0.001; OR = 3.12; CI = 1.6–6.1), 'wait and see' (p = <0.001; OR = 5.09; CI = 2.6–9.9), 'low prioritisation' (p = <0.001; OR = 2.11; CI = 1.9–5.8), 'self-medication' (p = <0.001; OR = 2.37; CI = 0.9–6.3), 'fatalism/nihilism' (p = <0.001; OR = 4.21; CI = 2.2–8.2) and 'denial' (p = <0.001; OR = 2.74; CI = 1.4–5.3) associated with longer TTP. 'Fear of diagnosis' not associated with longer TTP.

[9] 'I considered the symptom as harmless' (r = 0.34, p = 0.003), 'I considered the symptom as temporary' (r = 0.30; p = 0.01), 'my lifestyle is too complex' (r = 0.29; p = 0.01), 'I had nobody to talk to about the symptom' (r = 0.28; p = 0.02) and 'I thought I would wait a while before making an appointment' (r = 0.26; p = 0.02) associated with longer TTP.

[10] 'Thought doctor couldn't help' associated with shorter TTP (r = -.13, p < 0.05). No significant association between TTP and other barriers ('transportation problems', 'difficulty getting off work', 'not knowing where to go for help', 'just being too busy', 'thought it was not serious', 'not comfortable with doctor' and 'fear').

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
delays	al., 2000									
Reasons for delay in diagnosis	Schmid-Wendtner et al. (2002)	Interviewer	New	–	–	–	–	–	–	–
Competing events in the participants' lives	Scott et al. (2008)	Self-administered questionnaire	Existing (Modified for study) (Holmes & Rahe, 1967)	–	✓	–	–	–	–	↑
Reasons for delay	Skeppner et al. (2012)	Interviewer	New	–	–	–	–	–	–	–
Reasons for delay	Smith and Anderson (1985)	Self-administered questionnaire	New	–	–	–	–	–	–	=
Patient's perceived reasons for patient delay	Unger-Saldana et al. (2012)	Interviewer	New	✓	?	✓	✓	✓	–	–

Table 5 Measure/items used for 'Reasons for Delay'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Subjective patient-specific factors	Alam (2011)	Why did you wait to go to the doctor? (provide only the most important reasons) a) Thought it would go away b) Thought it was not important c) Thought you could treat it yourself d) Too busy e) Physician scheduling delay f) Had other personal/professional problems at the time g) Had other medical problems at the time h) Was afraid it might be something dangerous i) Had a bad experience with doctors or with surgery in the past j) Financial reasons/insurance problems k) Comments:_____
Reasons for delay	Bosl et al. (1981)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their reasons for delay: a) did not recognise the significance of the symptoms b) feared cancer c) attributed symptoms to the trauma they had sustained d) symptoms subsided e) merely procrastinated f) reason for delay was unknown
Reason for delay	Courtney et al. (2012)	What is the main reason you did not seek medical advice about [Symptom X] sooner? Please circle only one response. a) Thought it was haemorrhoids / piles b) Cleared up itself c) Thought it wasn't serious d) Decided to wait and see e) Didn't want to worry family or friends f) Thought doctor couldn't do anything g) Put it out of my mind – chose not to think about symptom h) Difficulty making an appointment i) Worried or scared it might be serious j) Not confident in discussing symptoms /doctor hard to talk to k) No time / busy / other things to think about l) Seeing a doctor would be unpleasant /embarrassing m) Other

Psychosocial Factor	Author (Year)	How specific factors were assessed
		N.B. Respondents' reason (response option verbatim) for never seeking medical advice following primary symptom episode and respondents' reason for delay (> 1 week) in seeking medical advice following their first primary symptom episode in the previous 5 years were combined by the authors
Reasons for delay	Doherty and MacKie (1986)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* a) lack of knowledge of the possible serious consequences of a new or growing cutaneous pigmented lesion b) difficult family circumstances such as chronic illness in another family member c) fear of the extent of possible surgical treatment
Barriers to seeking a medical consultation	Friedman et al. (2006)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Instrument consisted of an eight item checklist. Items included: a) hard to get an appointment b) hard to get off work c) cost d) rather not think about it e) worried it might be cancer f) worried about cancer treatment g) worried that I might lose my breast h) too long a wait at the clinic
Reasons delaying presentation	Kakagia et al. (2013)	Why didn't you come earlier? (tick all relevant) a) embarrassed b) work c) family care d) other e) fear of: diagnosis, investigations, treatment f) wait and see g) self-treated h) what will be will be i) don't like hospitals
Competing life priorities	Li et al. (2012)	At the time, other things occupied your mind and you did not have time to think much about your symptom? Response options: Likert scale ranging from 1 ('strongly agree') to 4 ('strongly disagree')
Factors which made it more	O'Mahony and Hegarty	What reasons (if any) made it more difficult for you or caused you to delay going to your General Practitioner

Psychosocial Factor	Author (Year)	How specific factors were assessed
difficult to visit GP	(2009)	(GP)? (Please tick the appropriate boxes). Reasons that made it difficult or caused me to delay going to my GP. Response options: strongly disagree, disagree, neither agree nor disagree, agree, strongly agree a) I had nobody to talk to about the symptom b) I considered the symptom as temporary , that it would improve over time c) I considered the symptom as harmless d) I was too busy e) My lifestyle is too complex, I felt that I did not have space in my life for health problems. f) My lifestyle is good, I did not want to change that by having the symptom investigated. g) I thought that if I improved my lifestyle (better diet, exercise) that the symptom would go away. h) I was taken up with family commitments i) I was taken up with work commitments j) I did not have suitable travel or transport available to me k) I was not registered with a GP l) I have a male GP, which made it difficult for me to attend m) I have no health insurance n) I had to wait for an appointment with my GP o) My past experience with the GP service was not positive p) I do not have confidence in the health service q) I did not want my GP or other health care personnel to examine my breasts. r) I was afraid of the symptom s) I was worried about the symptom t) I was anxious about the symptom u) I was unsure about the symptom v) I thought that I would wait for a while before making an appointment w) The cost of the medical appointment affected my decision x) I was afraid of the diagnosis y) I was afraid that I might have to have surgery z) I was worried about possible treatment I might require if diagnosed with breast cancer aa) I was worried about the impact of the diagnosis on my relationship with my partner bb) I was worried about the financial implications of the diagnosis cc) My past experience of having a friend/ family

Psychosocial Factor	Author (Year)	How specific factors were assessed
		member/ relative with cancer made it difficult or me to go to my GP dd) I have a strong religious faith, I thought I would wait and see what would happen. ee) I took medicine that I had at home to make the symptom better ff) I tried alternative therapies (or remedies) for a while to see if they would make the symptom better. gg) Other factors that made it more difficult for me or caused me to delay going to my GP (please explain): _____
Barriers to seeking help	Popescu et al. (2013)	Why didn't you come to the doctor earlier? (check all that apply) a) I didn't have time b) I thought that it will cure by itself c) I didn't think it was dangerous d) I live far from doctor's office e) I didn't obtain an earlier appointment f) I didn't know what specialty to address to g) I didn't have financial means h) I didn't take care first of other medical problems i) I had to take care first of family problems j) I couldn't take a day off from work k) I was afraid to go to the doctor l) I was afraid of surgery
Barriers to seeking medical care	Prohaska et al. (1990)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Respondents were given eight reasons for not seeing a doctor for their symptoms and asked to identify those that have affected their decision to seek medical care. Barriers included both patient generated and environment generated factors that were identified as barriers to timely medical care utilisation (Williams, 1981, as cited in Prohaska et al., 1990). Problem list included four 'logistic or environmental barriers' and four 'perception problems or attitudinal barriers'. Logistic or environmental barriers: a) transportation problems b) difficulty getting off work c) not knowing where to go for help d) just being busy Perception problems or attitudinal barriers: a) thought it was not serious b) not comfortable with doctor

Psychosocial Factor	Author (Year)	How specific factors were assessed
		c) fear d) thought doctor could not help
Barriers	Reifenstein (2007)	Measure used: "Melnyk's Barrier Scale" (Melnyk, 1990; adapted by Lauver, 1994). Barriers were rated on a 4-point scale ranging from 0 ('not at all') to 4 ('greatly'). Participants rated the degree to which 12 items influenced their decision to seek medical care for a breast symptom. The full list of items were not provided, but examples of barriers are "the high cost of transportation and/or parking" and "insurance (or medical coverage) does not cover a visit for a health problem." Other barrier items that were assessed included "the high cost of a health visit", "the long wait between making an appointment and the actual appointment" and "difficulty in finding time in my work day for an appointment"
Reasons for delays	Richard et al., 2000	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their reasons for delay a) Quiet appearance of the lesion together with the absence of systemic signs b) Absence of awareness about the urgency c) Occupational reasons d) Familial reasons e) Fear of diagnosis f) Passivity until family urged consultation g) Negligence h) Absence of pain N.B. These factors were only assessed when d2-d3 interval was more than 2 months [d2 is defined as when the individual identified the lesion as potentially dangerous; d3 is defined as the date when the lesion was first examined by a HCP].
Reasons for delay in diagnosis	Schmid-Wendtner et al. (2002)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their reasons for delay a) impression that lesion was benign or not important b) no delay c) afraid of physician's diagnosis

Psychosocial Factor	Author (Year)	How specific factors were assessed
		d) lesion undetected because of anatomical site e) too busy to consult a physician f) reasons remained unclear [Multiple responses were possible]
Competing events in the participants' lives	Scott et al. (2008)	Measure used: Modified version of the "Social Readjustment Scale" (Modified for study) (Holmes & Rahe, 1967)
Reasons for delay	Skeppner et al. (2012)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their reasons for delay: a) Embarrassment b) Fear of severe disease c) Lack of knowledge d) Thought it would disappear e) Temporary remission f) Nothing severe g) Can't remember h) Other reasons
Reasons for delay	Smith and Anderson (1985)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their reasons for delay a) difficulty getting an appointment b) menstrual related symptoms c) fear d) symptoms interpreted as not serious
Patient's perceived reasons for patient delay	Unger-Saldana et al. (2012)	Why did you not seek medical care sooner? I am going to read different options and you can respond 'yes' or 'no' to each. You did not seek medical care sooner… 1. Because you thought the problem would disappear on its own? 2. Because you did not know what health service to visit?? 3. Due to lack of money to use the health services? 4. Due to difficulty to leave work? 5. Because you have to care for a relative (a child, elderly or sick)? 6. Due to apathy or oversight? 7. Due to fear? 8. Because you were embarrassed about being checked?

Psychosocial Factor	Author (Year)	How specific factors were assessed
		9. For any other reason?

2.5.3.2 Reasons for seeking help

i. Robustness of measures

Six studies investigated reasons for seeking help (Brochez et al., 2001; Courtney et al., 2012; O'Mahony & Hegarty, 2009; Reifenstein, 2007; Richard et al., 2000; Unger-Saldana et al., 2012). **Table 6** documents the psychometric properties and TTP for 'Reasons for seeking help, whereas **Table 7** documents the measure/items used for 'Reasons for seeking help.

Two studies (Reifenstein, 2007; Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Utility was measured by Reifenstein (2007) via 13 outcome statements originally developed by Lauver (1992a). Responses are rated on a 11-point scale ranging from 0% to 100%, with two responses required for each item, one for expectations about outcomes of care seeking (e.g. 'I would be told that I have breast cancer') and a second for values of outcomes of care seeking (e.g. 'having the problem dealt with'). A utility score was calculated based on expectations and values of outcomes of help seeking. In Lauver's study (1992a) test-retest correlation for the average expectation score was $r = 0.71$ and Cronbach's alpha was $\alpha = 0.71$ and $\alpha = 0.78$ on two administrations. Test-retest correlation for the average value score was noted as $r = 0.54$ and Cronbach's alpha was $\alpha = 0.68$ and $\alpha = 0.73$ on two administrations. In Reifenstein's (2007) study, Cronbach's alpha was $\alpha = 0.97$ for the value outcomes. Reifenstein (2007) did not provide any details on the reliability for the expectations outcome.

Unger-Saldana et al. (2012) measured 'patient's reason for seeking medical care' by assessing numerous factors such as appearance of symptoms, persistence of symptoms and worsening of symptoms. Participants were asked to answer 'What made you decide to go to a doctor?' by selecting one of six options (e.g. 'The fact that time passed and discomfort still lingered on'). Face and content validity of the entire questionnaire was determined in the questionnaire development process.

ii. Relationship with TTP

'Reasons for help-seeking' were associated with shorter TTP in one study (O'Mahony & Hegarty, 2009). Two studies showed no significant relationship between 'reasons for seeking help' and TTP (Brochez et al., 2001, Reifenstein, 2007). Only one study used a scale with some evidence of reliability or validity (Reifenstein, 2007).

Table 6 Psychometric Properties and TTP for 'Reasons for seeking help'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Reason for consulting	Brochez et al. (2001)	Interviewer	New	–	–	–	–	–	–	=
Triggers for seeking medical advice	Courtney et al. (2012)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Factors which made it easier to visit GP	O'Mahony and Hegarty (2009)	Self-administered questionnaire	Existing (Modified for study) (Meechan et al., 2002)	–	–	–	–	–	–	↓[11]
Reasons for the rapidity of the visit to the physician	Richard et al. (2000)	Interviewer	New	–	–	–	–	–	–	–
Utility	Reifenstein (2007)	Self-administered questionnaire	Existing (Lauver, 1992a)	✓	✓	–	–	–	–	=
Patient's reason for seeking medical care	Unger-Saldana et al. (2012)	Interviewer	New	–	–	✓	✓	–	–	–

↑ = longer TTP; ↓ = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

[11] 'I considered the symptom as harmless' (r = 0.28; p = 0.01), 'the earlier I got it seen to the better' (r = 0.25; p = 0.02) and 'the nature of the symptom' (r = 0.25; p = 0.03) associated with shorter TTP.

Table 7 Measure/items used for 'Reasons for seeking help'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Reason for consulting	Brochez et al. (2001)	What was the reason for consulting this physician? a) other reason than the lesion b) worry, anxiety about the lesion c) advice of someone else d) cosmetic aspect/trouble by the lesion e) preventive skin examination f) medical advice when accompanying a family member on consultation g) combinations h) missing
Triggers for seeking medical advice	Courtney et al. (2012)	What in particular prompted you to consult a doctor about [Symptom X]? Please circle all that apply. a) Thought the symptom was serious b) Symptom didn't go away c) Opportunity to talk during doctor visit for other reason d) Family history of cancer e) Partner or family member suggested it f) Symptom didn't go away g) Thought the symptom was serious h) Opportunity to talk during doctor visit for other reason i) Other
Factors which made it easier to visit GP	O'Mahony and Hegarty (2009)	Which of the following list of factors helped or made it easier for you to go to your general practitioner (GP)? (Please tick the appropriate boxes) Factors that helped or made it easy for me to go to my GP. Response options: strongly disagree, disagree, neither agree nor disagree, agree, strongly agree: a) I was encouraged by a friend to visit my GP b) I was encouraged by my husband /partner to visit my GP c) I was encouraged by a family member to visit my GP d) I considered the symptom as harmless e) I have the power to influence my future health f) I thought that the earlier I got this symptom seen to, the better the outcome. g) I felt the need to consult (clarify the situation) with a health care professional h) I wanted to get a diagnosis i) I wanted to address a concern j) The nature of the symptom prompted me to go k) I thought the symptom was serious l) I was afraid of the symptom m) I was worried about the symptom

Psychosocial Factor	Author (Year)	How specific factors were assessed
		n) I was anxious about the symptom o) I was unsure about the symptom p) I was worried about the impact of the diagnosis on my relationship with my partner q) I had a medical card r) I had private health insurance s) I have a female GP, which made it easier for me to attend. t) I was motivated by advertising on the media which advised women to see their GP if they found a lump or any other problem with their breast u) I have religious beliefs, this helped me to go to the GP v) Other factors which helped or made it easy for me to go to the GP (Please Explain):
Reasons for the rapidity of the visit to the physician	Richard et al. (2000)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their reasons for seeking help a) Common sense b) Awareness about skin cancer c) Anxiety d) Family pressure e) Other reasons N.B. This was only assessed when d2-d3 interval was less than 2 months [d2 is defined as when the individual identified the lesion as potentially dangerous; d3 is defined as the date when the lesion was first examined by a HCP].
Utility	Reifenstein (2007)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Expectations and values of outcomes of care seeking were assessed with 13 outcome statements to calculate a utility score. Each item required two responses, one for the perceived likelihood of an outcome and a second for the perceived importance of an outcome. Full list of items was not provided, but an example of the values of outcomes of care seeking was: “having the problem dealt with”. Full list of items was not provided, but an example of the expectations about outcomes of care seeking was: “I would be told that I have breast cancer”. Participants were asked to rate their responses on an 11-point scale ranging from 0% (does not matter at all) to 100% (matters extremely), or 0% (not at all important) to 100%

Psychosocial Factor	Author (Year)	How specific factors were assessed
		(extremely important), with increments of 10.
Patient's reason for seeking medical care	Unger-Saldana et al. (2012)	What made you decide to go to a doctor? Please read all the answer options aloud. a) the onset of discomfort? b) the worsening of discomfort? c) the fact that time passed and discomfort still lingered on? d) the fact that discomfort interfered with some of your usual activities? e) advice from your family or your social network? f) or something else? (please specify) g) no answer

2.5.3.3 Knowledge

i. Robustness of measures

Eight studies investigated how knowledge affected actual TTP (Bowen & Rayner, 2002; Kumar et al., 2001; O'Mahony et al., 2013; Oliveria et al., 1999; Panzarella et al., 2014; Schmid-Wendtner et al., 2002; Scott et al., 2008; Smith et al., 2009). **Table 8** documents the psychometric properties and TTP for 'Knowledge', whereas **Table 9** documents the measure/items used for 'Knowledge'.

Three studies (Kumar et al., 2001; O'Mahony et al., 2013; Scott et al., 2008) used a scale with some evidence of reliability or validity.

Kumar et al. (2001) examined whether cancer can develop if tobacco is used as part of a 60 item questionnaire. No details on the items were provided. Test-retest reliability of the whole questionnaire was examined in a sample of 10 participants over seven days. The reliability of the final questionnaire was acceptable (ICC = 0.81).

O'Mahony et al. (2013)[12] examined women's breast cancer knowledge using a modified version of the "Breast Cancer Knowledge Scale" (Facione, Miaskowski, Dodd, & Paul, 2002). The scale consisted of 15 items describing potential breast cancer symptoms. Women were asked to indicate whether they thought changes are due to breast cancer using a 'yes/no/I don't know' scale. Items included 'persistent itching of the skin' or 'a lump under my arm'. The original version of the scale (Facione et al., 2002) has shown good internal consistency ($\alpha = 0.88$). Content and face validity in the study of O'Mahony et al. (2013) were determined by an expert panel of clinical and research experts. Content validity was further confirmed by ensuring that participants' breast changes reflected the breast changes outlined in the literature. O'Mahony et al. (2013) reported the average content validity index for the scale as 0.85.

Scott et al. (2008) examined knowledge and beliefs about oral cancer via the 36-item "Knowledge and beliefs about oral cancer" questionnaire (Humphris, Duncalf, Holt, & Field, 1999). In the questionnaire, knowledge items are grouped into five categories (cause, screening process, symptoms, occurrence and general questions about oral cancer) and answered using a 'true/false' format. No details on reliability or validity were reported by

[12] Where O'Mahony et al. (2013) is referenced in this chapter, further information was obtained from O'Mahony (2011)

Scott et al. (2008), but in the original study the questionnaire showed an acceptable reliability with KR-20 reported as 0.76 (Humphris et al., 1999). Humphris et al. (1999) determined criterion validity by the scale's ability to differentiate between four different groups of respondents ($F = 12.41$; $df = 3,143$; $p < .0001$).

ii. Relationship with TTP

Two studies with some evidence of reliability and validity found higher knowledge to be associated with shorter TTP (Scott et al., 2008; O'Mahony et al., 2013). Studies with limited or no evidence of reliability or validity reported mixed results, with no link between knowledge and TTP in a study by Kumar et al. (2001) and Oliveria et al. (1999) [knowledge of bleeding and scab not healing as a sign of skin cancer], knowledge of general oral health being linked to shorter TTP, as well as knowledge of oral cancer not being associated with TTP in a study by Panzarella et al. (2014), or that compared to no knowledge, knowing quite a lot was linked to longer TTP (Smith et al., 2009).

Table 8 Psychometric Properties and TTP for 'Knowledge'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Symptom Information	Bowen and Rayner (2002)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Cancer can develop if tobacco is used	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
Knowledge	Oliveria et al. (1999)	Interviewer	New	–	–	–	–	–	–	=[13]
Breast Cancer Knowledge	O'Mahony et al. (2013)	Self-administered questionnaire	Existing (Modified for study) (Facione et al., 2002)	✓	–	✓	✓	–	–	↓[14]
Knowledge of cancer (general or	Panzarella et al.	Interviewer	New	–	–	–	–	–	–	↓ =[15]

↑ = longer TTP; ↓ = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

[13] Knowledge of 'bleeding' (OR = 0.43; CI = 0.19-0.94) or 'scab not healing' (OR = 0.46; CI = 0.21-1.00) as a sign of skin cancer not associated with TTP.

[14] Shorter TTP associated with 'knowledge of breast symptom identity' (i.e. recognising the presenting symptom of a breast lump) (OR = 0.54; $p < 0.001$) and 'breast cancer knowledge' (i.e. responding 'yes' to 'a clear drainage from the nipple') (OR = 0.63; $p = 0.040$). Shorter TTP associated with 'knowledge relating to breast symptom identity' (i.e. a presenting symptom of 'nipple indrawn/changes') (OR = 4.80; $p = 0.005$).

[15] General knowledge of cancer (Poor vs. Basic: OR = 52.91; 95% CI = 51.25–6.76; $p = 0.013$) linked to shorter TTP. No significant association between TTP and knowledge of oral cancer.

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
oral)	(2014)									
Knowledge about cutaneous melanoma	Schmid-Wendtner et al. (2002)	Interviewer	New	–	–	–	–	–	–	–
Knowledge and beliefs about oral cancer	Scott et al. (2008)	Self-administered questionnaire	Existing (Humphris et al., 1999)	✓	–	–	–	–	✓	↓
Knowledge of lung cancer symptoms	Smith et al. (2009)	Interviewer	New	–	–	–	–	–	–	↑

Table 9 Measure/items used for 'Knowledge'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Symptom Information	Bowen and Rayner (2002)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked if they had not previously seen/heard any information about these symptoms
Cancer can develop if tobacco is used	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked if cancer can develop of tobacco is used Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Knowledge	Oliveria et al. (1999)	Melanoma is one form of skin cancer. Based on what you knew 1 year ago, which of the following mole/mark characteristics might have made you think at that time this could be melanoma or probably is melanoma? a) Dark or varied color b) Large diameter c) Abnormal shape (not round or oval) d) Change in shape, size, or color e) Bleeding f) Itching g) Scab that won't heal h) Don't know
Breast Cancer Knowledge	O'Mahony et al. (2013)	Measure used: Modified version of the "Breast Cancer Knowledge Scale" (Modified for study) (Facione et al., 2002) Below is a list of changes that can occur in the breast. Please indicate an "X" in the box that best describes whether these changes might be signs of breast cancer, in general. Please tick your response to each of the breast changes outlined below Response options: Yes, No, Don't know 1. Persistent itching of the skin 2. A breast lump I never noticed before 3. A lump under my arm 4. A hot reddened painful area 5. Constant pain in one area of the breast 6. A darkening of the skin 7. A little blood coming from one nipple 8. A thickened area in one breast

Psychosocial Factor	Author (Year)	How specific factors were assessed
		9. One nipple beginning to sink inwards 10. A sore or scab on one nipple 11. A clear drainage from one nipple 12. A change in the shape of one breast 13. A lump becoming larger 14. A dimpling in the skin of one breast 15. One breast getting larger Scale measures knowledge of breast changes associated with breast cancer calculated as the number of responses (1 to 15) endorsing 'yes' to each item on the scale ranging from 'low'(0 to 4), 'medium' (5 to 9) to 'high' (10 to 15).
Knowledge of cancer (general or oral)	Panzarella et al. (2014)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about Knowledge of cancer: a) Basic b) None c) Poor Knowledge of oral cancer: a) Basic b) None c) Poor
Knowledge about cutaneous melanoma	Schmid-Wendtner et al. (2002)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the source of knowledge about cutaneous melanoma: - Television and magazines - Conversation with friends - School/education - Physicians - No knowledge
Knowledge and beliefs about oral cancer	Scott et al. (2008)	Measure used: 36-item "Knowledge and beliefs about oral cancer" questionnaire (Humphris et al., 1999) Measure assesses knowledge of the aetiology, the screening process, and the symptoms of oral cancer. The scores range from 0 to 36, with higher scores representing more accurate knowledge.
Knowledge of lung cancer	Smith et al. (2009)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]*

Psychosocial Factor	Author (Year)	How specific factors were assessed
symptoms		Patients were asked about knowledge of lung cancer symptoms before diagnosis: a) Nothing b) A little c) Quite a lot d) Everything

2.5.3.4 Perceived Risk

i. Robustness of measures

Three studies investigated how 'perceived risk' affected TTP (Friedman et al., 2006; O'Mahony & Hegarty, 2009; Smith et al., 2009) and all used newly developed measures. **Table 10** documents the psychometric properties and TTP for 'Perceived Risk', whereas **Table 11** documents the measure/items used for 'Perceived Risk'.

Further details on the items and response options were provided by all authors. However, none of the authors stated whether any psychometric testing procedures were carried out in order to assess reliability or validity.

ii. Relationship with TTP

These studies found mixed results in relation to 'perceived risk' and TTP. In one study lower perceived risk was linked to shorter TTP (Friedman et al., 2006), whereas there was no significant relationship between perceived risk and TTP in a study by Smith et al. (2009).

Table 10 Psychometric Properties and TTP for 'Perceived Risk'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Perceived risk of breast cancer	Friedman et al. (2006)	Self-administered questionnaire	New	–	–	–	–	–	–	↓
Risk Perception	O'Mahony and Hegarty (2009)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Perceptions of self-risk of cancer	Smith et al. (2009)	Interviewer	New	–	–	–	–	–	–	=

Table 11 Measure/items used for 'Perceived Risk'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Perceived risk of breast cancer	Friedman et al. (2006)	What do you think your chances are for getting breast cancer some day? a) low b) moderate c) high
Risk Perception	O'Mahony and Hegarty (2009)	How would you rate your own personal risk of developing breast cancer over your lifetime? Please place a mark with an "X" on the line below: 0_____10 No Risk Very High Risk
Perceptions of self-risk of cancer	Smith et al. (2009)	Did you perceive yourself to be at any risk from lung cancer before your diagnosis? a) low risk/not at all b) average risk c) fairly/very high risk

2.5.3.5 Access to Healthcare

i. Robustness of measures

Seven studies evaluated the relationship between 'access to healthcare' and TTP (Adrien et al., 2014; Cameron & Hinton, 1968; Greer, 1974; Kumar et al., 2001; Li et al., 2012; O'Mahony et al., 2013; Scott et al., 2008). **Table 12** documents the psychometric properties and TTP for 'Access to Healthcare', whereas **Table 13** documents the measure/items used for 'Access to Healthcare'.

Three studies (Kumar et al., 2001; O'Mahony et al., 2013; Scott et al., 2008) used a scale with some evidence of reliability or validity.

Kumar et al. (2001) examined availability of transport, visiting a doctor for early detection and regular visit to the doctor as part of a 60 item questionnaire. No details on the items were provided. Test-retest reliability of the final questionnaire was acceptable (ICC = 0.81).

Health service utilisation (O'Mahony et al., 2013) was measured using a modified version of the 13 item "Perceived Access to Health Care Services Scale" (Facione, Dodd, Holzemer, & Meleis, 1997). The modified 11 item scale asked users to indicate how much they agree or disagree with the given statements in relation to their experience (e.g. 'Sometimes I go without the medical care I need because it is too expensive', 'I have easy access to my G.P.') on a four-point Likert scale ranging from 'strongly agree' (1) to 'strongly disagree' (4). Cronbach's alpha for the original scale was 0.78 (Facione et al., 1997) whereas O'Mahony et al. (2013) reported a lower Cronbach's alpha ($\alpha = 0.64$) for the modified scale. The average content validity index for the scale was 0.90 (O'Mahony et al., 2013). Further, personal experience of prejudice in health care delivery was assessed in this study via the "Personal Experience of Prejudice Scale" (Facione et al., 2002) which asks respondents to 'Please indicate how much you agree or disagree with the following statements in relation to your own experience'. Response options included 'Sometimes I have been ignored by a G.P. because I am a woman' or 'I have not always been treated respectfully by doctors or nurses' and were rated on a four-point Likert scale ranging from 'strongly agree' (1) to 'strongly disagree' (4). The average content validity index for the scale was 0.85 (O'Mahony et al., 2013). Both internal consistency (Cronbach's $\alpha = 0.42$) and mean inter-item correlations ($r = 0.24$) were low in O'Mahony's study (2013) in contrast to studies by Facione et al. (2002) and Facione and Facione (2007) who reported a Cronbach's alpha of α

= 0.71 and α = 0.73 respectively, with item total correlations ranging from r = 0.49 to r = 0.62.

Scott et al. (2008) examined perceived behavioural control to determine participants' perceived ability to obtain help for their oral symptoms. Participants were asked how easy or difficulty they found it to seek help for their oral symptoms. Responses were recorded on a three item, seven-point scale. The authors did not provide further details on the items, but stated that the scale demonstrated a Cronbach's alpha of α = 0.70.

ii. Relationship with TTP

Two studies, with some evidence of reliability or validity found no relationship between 'access to healthcare' and TTP (O'Mahony et al., 2013; Kumar et al. (2001). Two further studies noted a significant link between 'access to healthcare' and shorter TTP (Cameron & Hinton, 1968; Scott et al., 2008). These latter studies used measures that either had no evidence of reliability or validity (Cameron & Hinton, 1968), or only evidence of reliability (Scott et al., 2008).

Table 12 Psychometric Properties and TTP for 'Access to Healthcare'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Ease vs. difficulty to access	Adrien et al. (2014)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Difficulty to consult a general practitioner	Adrien et al. (2014)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Previous hospital experience	Cameron and Hinton (1968)	Self-administered questionnaire	New	–	–	–	–	–	–	↓
Attitude towards the family doctor	Greer (1974)	Interviewer	New	–	–	–	–	–	–	–
Regular visit to doctor in the past 12 years	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
Visiting doctor for early detection	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
Availability of transport	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	?
Financial Constraints	Li et al. (2012)	Interviewer	New	–	–	–	–	–	–	–

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Health Service System Utilisation (Perceived access)	O'Mahony et al. (2013)	Self-administered questionnaire	Existing (Modified for study) (Facione et al., 1997)	✓	–	–	✓	–	–	=
Health Service System Utilisation (Prejudice in health care delivery)	O'Mahony et al. (2013)	Self-administered questionnaire	Existing (Modified for study) (Facione et al., 2002)	✓	–	–	✓	–	–	=
Perceived Behavioural Control	Scott et al. (2008)	Self-administered questionnaire	New	✓	–	–	–	–	–	↓

Table 13 Measure/items used for 'Access to Healthcare'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Ease vs. difficulty to access	Adrien et al. (2014)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their ease vs. difficulty to access to: a) General practitioner b) HN specialist c) Radiological examination N.B. Each modality was tested binary ('yes' vs. 'no').
Difficulty to consult a general practitioner	Adrien et al. (2014)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their difficulty to consult a general practitioner/HN specialist/radiological examination: a) Means or time of transportation b) To get an appointment c) To get free of occupational obligations d) Financial cost e) Other Only one answer possible out of the item: 'no difficulty'.
Previous hospital experience	Cameron and Hinton (1968)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Does previous hospital experience influence delay? No response options provided.
Attitude towards the family doctor	Greer (1974)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their attitude towards the family doctor
Regular visit to doctor in the past 12 years	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their regular visit to the doctor in the past 12 years Response options: Likert Scale ranging from 1 ('no') to 5

Psychosocial Factor	Author (Year)	How specific factors were assessed
		('completely agree')
Visiting doctor for early detection	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about visiting their doctor for early detection Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Availability of transport	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the availability of transport Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Financial Constraints	Li et al. (2012)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* At the time money was short or you had other financial considerations? Responses rated on a single four-item Likert scale labelled from 1 ('strongly agree') to 4 ('strongly disagree')
Health Service System Utilisation (Perceived access)	O'Mahony et al. (2013)	Measure used: "Perceived Access to Healthcare Scale" (HSSU) (Modified for study) (Facione et al., 1997) The following statements describe your views on accessing the General Practitioner (GP). Please indicate how much you agree or disagree with the following statements in relation to your own experience: Response Options: Strongly disagree, disagree, agree, strongly agree 1. Sometimes I go without the medical care I need because it is too expensive. 2. The GP office should be open for more hours than it is. 3. The GP office is conveniently located. 4. GP's often do not listen to people 5. I have easy access to my GP 6. I have a female GP which makes it easier for me to attend 7. Prior to the occurrence of this breast symptom, I have not been to see my GP for at least two years 8. When it comes to health care visits, transportation is a big

Psychosocial Factor	Author (Year)	How specific factors were assessed
		problem for me 9. I see a different GP almost every time I get an appointment. 10. I have a GP with whom I feel comfortable talking to when I need medical care 11. It is difficult for me to go to the GP as I do not have a medical card Score ranges from 11 to 44. High scores indicate good perceptions of access to services and vice versa. Scale assesses perceived access: cost; convenience; relationship with HCP.
Health Service System Utilisation (Prejudice in health care delivery)	O'Mahony et al. (2013)	Measure used: "Personal Experience of Prejudice Scale" (PEP) (Modified for study) (Facione et al., 2002) The following statements describe your views on accessing the General Practitioner (GP). Please indicate how much you agree or disagree with the following statements in relation to your own experience: Response Options: Strongly disagree, disagree, agree, strongly agree 1. Sometimes I have been ignored by a GP because I am a woman 2. I have not always been treated respectfully by doctors and nurses 3. I have experienced discrimination in a GP's office 4. My own health has never been affected by discrimination Scores range from -2 ('strongly disagree') to +2 ('strongly agree'). Score range: -8 to +8.
Perceived Behavioural Control	Scott et al. (2008)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Measure of perceived behavioural control to obtain an estimation of participants perceived ability to receive help for oral symptoms. On a three-item, seven-point scale, participants were asked how easy or difficult they found it to seek help for oral symptoms in general. Scores ranged from 3 to 21, with higher scores representing more perceived behavioural control.

2.5.3.6 Emotional response to symptoms

i. Robustness of measures

Thirteen studies investigated how an emotional response to symptoms affected actual TTP (Andersen et al., 1995; Cameron & Hinton, 1968; Forghieri et al., 2010; Friedman et al., 2006; Hashim et al., 2010; Li et al., 2012; O'Mahony & Hegarty, 2009; O'Mahony et al., 2013; Panzarella et al., 2014; Reifenstein, 2007; Risberg et al., 1996; Scott et al., 2008; Unger-Saldana et al., 2012). **Table 14** documents the psychometric properties and TTP for 'Emotional response to symptoms', whereas **Table 15** documents the measure/items used for 'Emotional response to symptoms'.

Eight studies (Forghieri et al., 2010; Friedman et al., 2006; Hashim et al., 2010; O'Mahony & Hegarty, 2009; O'Mahony et al., 2013; Reifenstein, 2007; Scott et al., 2008; Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Five studies (Forghieri et al., 2010; Friedman et al., 2006; O'Mahony & Hegarty, 2009; O'Mahony et al., 2013; Scott et al., 2008) used (a modified version of) the "Symptom Distress Scale" (Meechan, Collins, & Petrie, 2003). With the help of this scale, respondents are asked to indicate the extent to which they feel mood states (e.g. 'afraid'; 'anxious'; 'distressed'; 'scared') when first noticing their symptoms on a five-item Likert scale from 1 ('very slightly') to 5 ('very much'). Cronbach's alpha was $\alpha = 0.89$ in the original study (Meechan et al., 2003) and ranged from $\alpha = 0.88$ to $\alpha = 0.94$ in the five studies that used the (modified version of the) "Symptom Distress Scale".

Hashim et al. (2010) investigated concern of rectal bleeding via a self-administered questionnaire. The authors did not provide further details on the items used, but noted that face validity was determined by a pre-test in six subjects. Further, the questionnaire was validated by an expert panel consisting of a colorectal surgeon, primary care physicians and a psychiatrist.

Reifenstein (2007) measured fear in relation to symptom interpretation by an 11-item "Fear Scale", which was developed for the study to measure correlation of fear with days delayed in seeking care. Reifenstein (2007) did not provide the full scale, but stated that participants were asked questions such as 'How fearful were you that your breast change was abnormal?'. Response options ranged from 'not at all fearful' (0) to 'extremely fearful' (4). The 'Fear Scale' demonstrated good reliability in both the pilot (Cronbach's $\alpha = 0.97$)

and actual study (Cronbach's α = 0.95). Face validity of the questionnaire was assessed by a panel of nursing experts and a team of five psychological experts.

Initial worry was assessed by Unger-Saldana et al. (2012) as part of the 'Patient initial interpretation of symptoms' dimension within the questionnaire. Participants were asked to indicate 'How worried were you at the time?' ('not at all', 'a little', 'moderately', 'or a lot'). Convergent and divergent validity were examined and the initial worry item demonstrated moderate to strong degrees of correlation with other items within the 'Patient initial interpretation of symptoms' dimension (r = 0.52 to r = 0.72) and no or low correlations with items from other dimensions. Face and content validity of the entire questionnaire was assessed in the questionnaire development process.

ii. Relationship with TTP

Regardless of the evidence of reliability or validity for the measures of emotion, the findings for a link between 'emotional response' and TTP were mixed, varying between no association and emotion leading to shorter TTP (Cameron & Hinton, 1968, Hashim et al., 2010; Li et al., 2012, O'Mahony & Hegarty, 2009, O'Mahony et al., 2013). Findings differed between emotions, for instance, in the study by O'Mahony et al. (2013) only anxiety was related to shorter TTP. Two studies (Panzarella et al., 2014; Risberg et al., 1996) found an association between emotion [distress (Risberg et al., 1996) and denial (Panzarella et al., 2014)]. All of the other emotional responses examined by Panzarella et al. (2014; 'fear', 'carelessness', 'medical services mistrust') revealed no significant relationship. There was no association between TTP and emotional distress in a study by Friedman et al. (2006).

Table 14 Psychometric Properties and TTP for 'Emotional response to symptoms'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Illness inference (Negative affect)	Andersen et al. (1995)	Interviewer	New	–	–	–	–	–	–	
Degree of anxiety on discovering the lump in the breast	Cameron and Hinton (1968)	Self-administered questionnaire	New	–	–	–	–	–	–	↓
Attitude to the forthcoming operation	Cameron and Hinton (1968)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Emotional response	Forghieri et al. (2010)	Self-administered questionnaire	Existing (Meechan et al., 2003)	✓	–	–	–	–	–	–
Initial emotional response to noticing breast symptom	Friedman et al. (2006)	Self-administered questionnaire	Existing (Modified for study) (Meechan et al., 2003)	✓	–	–	–	–	–	=
Concern of	Hashim et al.	Self-	New	–	–	✓	✓	–	–	↓

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
rectal bleeding	(2010)	administered questionnaire								
Fear of cancer diagnosis	Li et al. (2012)	Interviewer	New	–	–	–	–	–	–	
Fear in response to symptom(s)	Li et al. (2012)	Interviewer	New	–	–	–	–	–	–	↓
Symptom preoccupation	Li et al. (2012)	Interviewer	New	–	–	–	–	–	–	↓
Emotional response to symptom discovery	O'Mahony and Hegarty (2009)	Self-administered questionnaire	Existing (Modified for study) (Meechan et al., 2003)	✓	–	–	✓	–	–	↓[16]
Emotional response when first noticing breast symptom	O'Mahony et al. (2013)	Self-administered questionnaire	Existing (Modified for study) (Meechan et al., 2003)	✓	–	–	–	–	–	↓[17]

↑ = longer TTP; ↓ = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

[16] Emotional response of being 'afraid' on symptom discovery (OR = 0.37; p = 0.005) associated with shorter TTP.

[17] Emotional response of being 'anxious' on symptom discovery (r = 0.31; p = 0.003) associated with shorter TTP.

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Emotional responses to the detection of potentially threatening oral symptoms	Panzarella et al. (2014)	Interviewer	New	–	–	–	–	–	–	= ↑[18]
Fear	Reifenstein (2007)	Self-administered questionnaire	New	✓	–	✓	–	–	–	=
Distress	Risberg et al. (1996)	Self-administered questionnaire	New	–	–	–	–	–	–	↑
Emotional distress	Scott et al. (2008)	Self-administered questionnaire	Existing (Modified for study) (Meechan et al., 2003)	✓	–	–	–	–	–	=
Initial worry	Unger-Saldana et al. (2012)	Interviewer	New	–	–	✓	✓	✓	–	–

[18] Emotional response of 'denial' associated with longer TTP (True vs. False: OR = 56.84; 95% CI = 52.31–20.24; p < 0.01). No significant relationship between TTP and other emotional responses ('fear', 'carelessness', 'medical service mistrust').

Table 15 Measure/items used for 'Emotional response to symptoms'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Illness inference (Negative affect)	Andersen et al. (1995)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Sets of nine point scales (1 = 'not at all' to 9 = 'extremely') used to assess fear, anxiety and depression in response to symptoms on each date. Fear defined as the man of responses to questions of how fearful, scared and afraid their symptoms made participants feel. Similar comparisons made for the affects of anxiety (worried, anxious, nervous) and depression (sad, down-hearted, blue) and an overall measure of negative affect for each critical date was defined as the grand mean of the nine scales.
Degree of anxiety on discovering the lump in the breast	Cameron and Hinton (1968)	Were you worried when you discovered a lump in your breast? a) very worried b) moderately worried c) mildly worried d) only slightly worried e) not worried at all
Attitude to the forthcoming operation	Cameron and Hinton (1968)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked how they felt at the thought of having an operation. Response options: a) very confident b) confident c) fairly confident d) nervous e) very nervous.
Emotional response	Forghieri et al. (2010)	Measured used: "Symptom Distress Scale" (Modified for study) (Meechan et al., 2003) Participants rated on a five-point scale (1 = 'not at all' to 5 = 'very much') the extent they felt afraid, anxious, distressed or scared when they first discovered their breast symptom(s).
Initial emotional response to noticing breast symptom	Friedman et al. (2006)	Measure used: "Symptom Distress Scale" (Modified for study) (Meechan et al., 2003) Participants rated on a five-point scale ranging from 1 ('not at all') to 5 ('very much') the extent they felt each of four mood states ("afraid," "anxious," "distressed" and "scared")

Psychosocial Factor	Author (Year)	How specific factors were assessed
		when they first discovered their breast symptom(s).
Concern of rectal bleeding	Hashim et al. (2010)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their concern of rectal bleeding Response options: a) Not worried b) A little worried c) Worried d) Very worried
Fear of cancer diagnosis	Li et al. (2012)	At the time were you scared of finding out what it might be when you first discovered your symptom(s)? Response option: four-item Likert scale ranging from 1 ('strongly agree') to 4 ('strongly disagree')
Fear in response to symptom(s)	Li et al. (2012)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the extent of fear upon first noticing breast symptoms rated on a four-item Likert scale from 1 ('little') to 4 ('severe')
Symptom preoccupation	Li et al. (2012)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the preoccupation with their symptom during the week following the symptom discovery, rated on a four-item Likert scale ranging from 1 ('little time') to 4 ('all the time')
Emotional response to symptom discovery	O'Mahony and Hegarty (2009)	Measure used: "Symptom Distress Scale" (Modified for study) (Meechan et al., 2003) Responses rated on five-item Likert scale ranging from 1 ('not at all') to 5 ('very much')
Emotional response when first noticing breast symptom	O'Mahony et al., (2013)	Measure used: "Symptom Distress Scale" (Modified for study) (Modified version) (Meechan et al., 2003) Below are a number of words that describe different feelings and emotions. Read each word and then tick the appropriate answer in the space next to the word. Please indicate to what extent you felt this way when you first noticed your breast symptom(s). Response options: very slightly or not at all, a little bit, moderately, quite a bit, very much

Psychosocial Factor	Author (Year)	How specific factors were assessed
		When I first noticed my symptom(s), I felt a) afraid b) anxious c) distressed d) scared e) depressed f) angry g) unsure
Emotional responses to the detection of potentially threatening oral symptoms	Panzarella et al. (2014)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Denial (True/False) Fear (True/False) Carelessness (True/False) Medical services mistrust (True/False)
Fear	Reifenstein (2007)	Measure used: "Fear Scale" (Reifenstein, 2007) Complete items or response options not provided. Example of question: "How fearful were you that your breast change was abnormal?" Responses rated on 11-item Likert type scale ranging from 0 ('not at all fearful') to 4 ('extremely fearful')
Distress	Risberg et al. (1996)	Would you please grade the distress of the different delay periods mentioned? 0 means no problem at all, 10 means very distressing. The waiting period before the appointment with the GPs 0----------10
Emotional distress	Scott et al. (2008)	Measure used: "Symptom Distress Scale" (Modified for study) (Meechan et al., 2003) Responses rated on five-item Likert scale ranging from 1 ('not at all') to 5 ('very much')
Initial worry	Unger-Saldana et al. (2012)	How worried were you at the time? Please read all the options aloud. a) Not at all? b) A little? c) Moderately? d) Or a lot? e) No answer

2.5.3.7 Symptom Interpretation

i. Robustness of measures

Fourteen studies assessed 'symptom interpretation' (Andersen et al., 1995; Bowen & Rayner, 2002; Greer, 1974; Hashim et al., 2010; Kakagia et al., 2013; Kumar et al., 2001; Li et al., 2012; Mansson et al., 1993; O'Mahony et al., 2013; Oliveria et al., 1999; Panzarella et al., 2014; Ristvedt & Trinkaus, 2005; Smith & Anderson, 1985; Unger-Saldana et al., 2012). **Table 16** documents the psychometric properties and TTP for 'Symptom Interpretation', whereas **Table 17** documents the measure/items used for 'Symptom Interpretation'.

Four studies provided some evidence of the reliability or validity of the measure used (Hashim et al., 2010; Kumar et al., 2001; O'Mahony et al., 2013; Unger-Saldana et al., 2012).

Hashim et al. (2010) investigated causes of rectal bleeding according to patients' opinion via a self-administered questionnaire. The authors did not provide further details on the items used, but noted that face validity was determined by a pre-test in six subjects. Further, the questionnaire was validated by an expert panel.

Kumar et al. (2001) examined perceived necessity of consulting a doctor for small ulcers in the mouth for those who use tobacco as part of a 60 item questionnaire. No details on the items were provided. Test-retest reliability of the final questionnaire was acceptable (ICC = 0.81).

O'Mahony et al. (2013) used an adapted version of the "Illness Perception Questionnaire" (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996) to measure beliefs regarding breast cancer. The 26-item adapted version measured beliefs relating to symptom cause, timeline, consequences, cure/control and symptom outcome. In O'Mahony et al.'s study (2013) internal consistency coefficients ranged from $\alpha = 0.50$ to $\alpha = 0.79$, whereas in the original study (Weinman et al., 1996) reliability coefficients ranged from $\alpha = 0.73$ to $\alpha = 0.82$. Two items on symptom outcome were added to the modified version of the IPQ using questions adapted from a qualitative study conducted by Burgess et al. (1998). Further, O'Mahony et al. (2013) noted that the average content validity index for scales was 0.80 for duration, 0.90 for consequences and 0.90 for cure/control. The average content validity index for items ranged from 0.80 to 1.00 for cause and 1.00 for outcome of symptoms (O'Mahony et

al., 2013). Concurrent, discriminative and predictive validity and test-retest reliability of the IPQ was established in the original study (Weinman et al., 1996).

Perceived seriousness was assessed by Unger-Saldana et al. (2012) as part of the 'Patient initial interpretation of symptoms' questionnaire dimension. Participants were asked 'When you first noticed it, how serious did you think it was?' ('not serious at all', 'not very serious', ' moderately serious', 'serious', 'or very serious') and 'When you first noticed it, did you think it could be cancer?' ('yes' or 'no'). Convergent and divergent validity were examined and items within the 'Patient initial interpretation of symptoms' dimension demonstrated moderate to strong degrees of correlation with each other (r =0 .52 to r = 0.72) and not with items from other dimensions. Internal consistency for this dimension was reported as Cronbach's $\alpha = 0.77$ ($p < .001$). Face and content validity of the entire questionnaire was assessed in the questionnaire development process. As noted earlier, test-retest examinations were conducted, but the authors did not indicate the test-retest correlation for each separate dimension of the questionnaire.

ii. Relationship with TTP

'Symptom interpretation' was found to be related to TTP in six studies (Andersen et al., 1995; Greer, 1974; Kakagia et al., 2013; Oliveria et al., 1999; O'Mahony et al., 2013; Panzarella et al., 2014). There was no association between 'symptom interpretation' and TTP in two studies (Mansson et al., 1993, Smith & Anderson, 1985). Only one study used a measure with evidence of reliability and validity (O'Mahony et al., 2013).

Table 16 Psychometric Properties and TTP for 'Symptom Interpretation'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Environmental distractions	Andersen et al. (1995)	Interviewer	New	–	–	–	–	–	–	–
Illness inference (Symptom salience, motivation to determine the cause of symptoms, perceived seriousness)	Andersen et al. (1995)	Interviewer	New	–	–	–	–	–	–	↓[19]
Awareness of the significance of their symptoms	Bowen and Rayner (2002)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Initial reaction to Breast Symptoms	Greer (1974)	Interviewer	New	–	–	–	–	–	–	↑
Causes or rectal bleeding according to patients opinion	Hashim et al. (2010)	Self-administered questionnaire	New	–	–	✓	✓	–	–	–

[19] Patients reported motivation to evaluate their symptoms ($r = -0.42$; $p < 0.05$) and more dominant cancer inferences when symptoms first detected ($r = -0.32$; $p < 0.01$) associated with shorter TTP.

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Symptom Interpretation	Kakagia et al. (2013)	Interviewer	New	–	–	–	–	–	–	↑
Necessity of consulting a doctor for small ulcers in the mouth for tobacco users	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	?
Symptom Interpretation	Li et al. (2012)	Interviewer	Existing (Burgess et al., 1998)	–	–	–	–	–	–	–
How seriously the patients viewed their first symptoms of bladder cancer	Mansson et al. (1993)	Self-administered questionnaire	New	–	–	–	–	–	–	=
Beliefs relating to symptom cause, timeline, consequences, curability/control and outcome	O'Mahony et al. (2013)	Self-administered questionnaire	Existing (Modified for study)(Burgess et al., 1998) (Weinman et al., 1996)	✓	✓	–	✓	✓	✓	↑[20]
Low awareness of	Oliveria et	Interviewer	New	–	–	–	–	–	–	↑

↑ = longer TTP; ↓ = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

[20] Longer TTP associated with women's belief in longer symptom duration (OR = 1.18; p = 0.023).

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
melanoma signs/ symptoms	al. (1999)									
Initial self-diagnosis	Panzarella et al. (2014)	Interviewer	New	–	–	–	–	–	–	↑
Complete unawareness	Panzarella et al. (2014)	Interviewer	New	–	–	–	–	–	–	↑
Recognition of symptom seriousness	Ristvedt and Trinkaus (2005)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Attributions about the cause of their symptoms	Ristvedt and Trinkaus (2005)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Perceived cause	Smith and Anderson (1985)	Self-administered questionnaire	New	–	–	–	–	–	–	=
Perceived seriousness	Smith and Anderson (1985)	Self-administered questionnaire	New	–	–	–	–	–	–	=
Perceived seriousness	Unger-Saldana et al. (2012)	Interviewer	New	✓	?	✓	✓	✓	–	–

Table 17 Measure/items used for 'Symptom Interpretation'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Environmental distractions	Andersen et al. (1995)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Women rated on four nine point scales (1 = 'not at all' to 9 = 'extremely') how boring, busy and challenging her life was on each critical day, and how many responsibilities she felt she had at the time (1 = 'none' to 9 = 'many'). The mean response to these scales served as an index of external distraction which might affect attention available to detect and interpret symptoms.
Illness inference (Symptom salience, motivation to determine the cause of symptoms, perceived seriousness)	Andersen et al. (1995)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Symptom salience: Women asked to rate on nine point scales (1 = 'not at all' to 9 = 'extremely') how "painful", "attention-getting", "noticeable" and "difficult to ignore" their symptoms were. Salience was defined as the mean of these four ratings. Motivation to determine the cause of symptoms: Women provided with exemplars indicative of strong motivation (e.g. "I talked to someone about it", "I looked for other symptoms") and were asked to rate their motivation to determine the cause of their symptoms. Rating were made on a nine point scale (1 = 'I couldn't have cared less' to 9 = 'I was extremely motivated to determine the cause'). One such rating was obtained for the set of symptoms experienced on each date. Perceived seriousness: Each explanation for symptom was rated on a Likert scale ranging from 1 ('this is a healthy/normal experience') to 9 ('this is a very ill/life threatening condition') Global rating of the perceived seriousness of her physiological condition (which would include the entire symptom picture)was rated on a Likert scale ranging from 1 ('it was a healthy/normal life experience') to 9 ('it was a very ill/life threatening condition')
Awareness of the significance of their symptoms	Bowen and Rayner	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]*

Psychosocial Factor	Author (Year)	How specific factors were assessed
	(2002)	a) The symptom that prompted a visit to their GP b) Awareness of the significance of their symptoms
Initial reaction to Breast Symptoms	Greer (1974)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their initial reaction to breast symptoms Response options: a) Definitely not serious b) Possibly serious c) Definitely serious
Causes or rectal bleeding according to patients opinion	Hashim et al. (2010)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their causes or rectal bleeding according to patients opinion Response options: a) Haemorrhoids b) Dietary factors c) Constipation d) Cancer e) Ulcer f) Overwork g) Medication h) Don't know
Symptom Interpretation	Kakagia et al. (2013)	You think your lesion a) is not serious b) is not cancer c) may be cancer
Necessity of consulting a doctor for small ulcers in the mouth for tobacco users	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the necessity of consulting a doctor for small ulcers in the mouth for tobacco users Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Symptom Interpretation	Li et al. (2012)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Women were asked what their initial symptom attribution

Psychosocial Factor	Author (Year)	How specific factors were assessed
		was on symptom discovery (Burgess et al, 1998). Symptom attributions were classified as “cancer” or “benign”.
How seriously the patients viewed their first symptoms of bladder cancer	Mansson et al. (1993)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked if they had regarded their initial symptoms regarded as: a) Serious b) Not serious
Beliefs relating to symptom cause, timeline, consequences, curability/control and outcome	O'Mahony et al. (2013)	Measures used: 1. Symptom attribution/outcome (Burgess et al., 1998) (Modified for study) *[Details of measure and/or items not provided]* 2. “Illness Perception Questionnaire” (IPQ) (Weinman et al., 1996) (Modified for the study): I am interested in your own views (beliefs) about your breast symptom and what it means to you. Please indicate how much you agree or disagree with the following statements about your breast symptom: Response options: Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree Cause: 1. The symptom was caused by a germ or virus 2. Diet played a major role in causing the symptom 3. Pollution in the environment caused the symptom 4. The symptom is hereditary- it runs in my family 5. The symptom occurred just by chance 6. Stress was a major factor in causing my breast symptom 7. My breast symptom was caused by my own behaviour 8. Other people played a major role in causing my breast symptom to occur 9. My state of mind played a major role in causing my breast symptom Duration: 10. My breast symptom will last for a short time 11. My breast symptom is likely to be permanent rather than temporary 12. My breast symptom will last for a long time

Psychosocial Factor	Author (Year)	How specific factors were assessed
		Consequences: 13. My breast symptom is a serious condition 14. My breast symptom has a major effect on my life 15. My breast symptom is easy to live with 16. My breast symptom has not had much effect on my life 17. My breast symptom has strongly affected the way others see me 18. My breast symptom has had serious economic & financial consequences for me 19. My breast symptom has strongly affected the way I see myself as a person Cure/ Control: 20. My breast symptom will improve in time 21. There is a lot I can do to control my breast symptom 22. There is very little that can be done to control my breast symptom 23. Recovery from my breast symptom is largely dependent on chance or fate 24. What I do can determine whether the symptom gets better or worse Outcome of symptom: 25. My breast symptom could be due to breast cancer 26. My breast symptom could be due to a non-threatening/less serious/benign breast problem
Awareness of melanoma signs/ symptoms	Oliveria et al. (1999)	Prior to your biopsy, did you ever think about your skin, how it looked, or whether there were any changes; whether there were any abnormal marks? Response options: Yes/No
Initial self-diagnosis	Panzarella et al. (2014)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the initial self-diagnosis a) Cancer b) Non-threatening condition c) Unable to self-diagnose
Complete unawareness	Panzarella et al. (2014)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their unawareness

Psychosocial Factor	Author (Year)	How specific factors were assessed
		Response options: False/True
Recognition of symptom seriousness	Ristvedt and Trinkaus (2005)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their recognition of symptom seriousness Response options: a) Not b) A little c) Somewhat d) Very e) Extremely
Attributions about the cause of their symptoms	Ristvedt and Trinkaus (2005)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their attributions about the cause of their symptoms Response options: a) Symptoms not due to cancer b) Symptoms due to cancer c) Uncertain d) Haemorrhoids e) Diet f) Physical injury or stress g) Miscellaneous causes (such as ulcers, diverticulitis, or other less threatening medical conditions)
Perceived cause	Smith and Anderson (1985)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about the perceived cause of symptoms Response options: a) Menopause b) Don't know c) Cancer or cyst d) Menstrual/reproductive problem N.B. Some causes, such as indigestion, infection, weight gain, nerves not categorised and were deleted from results table
Perceived	Unger-	When you first noticed it, how serious did you think it

Psychosocial Factor	Author (Year)	How specific factors were assessed
seriousness	Saldana et al. (2012)	was? Please read all the options aloud 1. Not serious at all? 2. Not very serious? 3. Moderately serious? 4. Serious? 5. Or very serious? 6. No answer

2.5.3.8 Social Factors

i. Robustness of measures

The extent to which 'social factors' affected TTP was assessed in ten studies (Bowen & Rayner, 2002; Cameron & Hinton, 1968; Cochran et al., 1986; Greer, 1974; Hashim et al., 2010; Kumar et al., 2001; Li et al., 2012; O'Mahony et al., 2013; Reifenstein, 2007; Unger-Saldana et al., 2012). **Table 18** documents the psychometric properties and TTP for 'Social Factors', whereas **Table 19** documents the measure/items used for 'Social Factors'.

Six studies provided some evidence of the reliability or validity of the measure (Cochran et al., 1986; Hashim et al., 2010; Kumar et al., 2001; O'Mahony et al., 2013; Reifenstein, 2007; Unger-Saldana et al., 2012).

Hashim et al. (2010) investigated seeking advice via a self-administered questionnaire. The authors did not provide further details on the items used, but noted that face validity was determined by a pre-test in six subjects. Further, the questionnaire was validated by an expert panel.

Marital satisfaction was assessed by Cochran et al. (1986) using the "Dyadic Adjustment Scale" (Spanier, 1976). The 32-item scale was used to assess dyadic satisfaction, dyadic cohesion, dyadic consensus and affectional expression with scores ranging from 0 to 151. Although Cochran et al. (1986) reported no further details on the reliability of the scale Cronbach's alpha was reported as $\alpha = 0.96$ in the original study by Spanier (1976). Content and construct validity of the scale was established in the original study (Spanier, 1976). Further, factor analysis of the final 32 item scale revealed that the scale measures the theoretical construct to some extent. In addition to the "Dyadic Adjustment Scale" (Spanier, 1976) participants also completed measures of tangible support (adapted from Schaefer, Coyne & Lazarus, 1981) using a 9-item Guttman scale. The full list of items was not provided, but participants were asked, for example, if there was someone who could help them with the housework or who they borrowed money from. Cochran et al. (1986) did not state whether tangible support was subjected to a formal assessment of validity and reliability. However, in the original study internal consistency for the 9-item tangible support scale was $\alpha = 0.31$ and test-retest reliability was reported as $r = 0.56$ (Schaefer et al., 1981).

Kumar et al. (2001) examined whether participants were escorted by someone, whether any family member, relative or friends had cancer and family tension due to long treatment. No details on the items were provided. Test-retest reliability was acceptable (ICC = 0.81).

O'Mahony et al. (2013) examined constraints on help-seeking via an adapted version of Facione and Facione's (2007) 17 item "Constraint scale". In O'Mahony et al.'s study (2013) the scale was modified to contain only four items questioning women on: work commitments, degree to which the partner or spouse was an influence on the women having a breast examination, caring commitments (relative or child) and having someone to talk to about the symptom. Items were rated as 'yes', 'no' and 'not applicable'. Cronbach's alpha was reported as $\alpha = 0.76$ in the original study (Facione et al., 2002). O'Mahony et al. (2013) noted that reliability for this scale was not established as the scores were not summed. The content validity index for the adapted version was 0.88.

Reifenstein (2007) examined social norm in relation to help-seeking behaviour using a scale developed by Lauver (1994). The scale measures participants' perceptions of how much four different people (female friend, husband/partner, mother, and female relative) had an effect on their help-seeking behaviour. Reifenstein (2007) did not provide the full items of the scale, but noted that participants were asked to respond on a 4-point scale ranging from 1 ('not at all') to 4 ('extremely necessary'). Cronbach's alpha was $\alpha = 0.97$ in Reifenstein's study (2007). In the original study Cronbach's alpha ranged from $\alpha = .84$ to $\alpha = .88$, and test-retest reliability was $r = 0.67$ (Lauver, 1994).

Emotional support was assessed by Unger-Saldana et al. (2012) as part of the 'Social network support for seeking medical attention' dimension of the questionnaire. Participants were asked 'Who did you first talk to about your health problem?" and then asked to state how many months or days it took them between first noticing their discomfort and talking to the person named previously about it. Convergent and divergent validity were examined, however items within the 'Social network support for seeking medical attention' dimension correlated poorly with each other ($r = < 0.30$). The authors also indicated that internal consistency (Cronbach's alpha) was low, resulting in the items being used individually rather than a summed scale. Face and content validity of the entire questionnaire was assessed in the questionnaire development process.

ii. Relationship with TTP

For those measures with some evidence of validity, ‘social factors’ were generally linked to shorter TTP (Cochran et al., 1986; Hashim et al., 2010; O'Mahony et al., 2013). Those measures that lacked validity often showed no association with TTP (Cochran et al., 1986; Kumar et al., 2001; Reifenstein, 2007), although two studies using measures with no evidence of reliability or validity also linked ‘social factors’ to shorter TTP (Cochran et al., 1986; Li et al., 2012).

Table 18 Psychometric Properties and TTP for 'Social Factors'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Encouragement from others to see their GP	Bowen and Rayner (2002)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Knowledge of others with mammary tumours	Cameron and Hinton (1968)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Willingness to tell others about personal troubles	Cameron and Hinton (1968)	Self-administered questionnaire	New	–	–	–	–	–	–	–
Emotional Support	Cochran et al. (1986)	Interviewer and self-administered questionnaire	Existing (Modified for study) (Stewart, 1983, as cited in Cochran et al., 1986)	–	–	–	–	–	–	↓
Tangible Support	Cochran et al. (1986)	Interviewer and self-administered questionnaire	Existing (Modified for study) (Schaefer et al., 1981)	?	✓	–	–	–	–	=
Marital Satisfaction	Cochran et al. (1986)	Interviewer and self-administered questionnaire	Existing (Modified for study) (Spanier, 1976)	✓	–	–	✓	✓	✓	↓
Experience of mastectomy among	Greer (1974)	Interviewer	New	–	–	–	–	–	–	–

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
family and friends										
Seeking advice	Hashim et al. (2010)	Self-administered questionnaire	New	–	–	✓	✓	–	–	↓
Escorted by someone	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
Any family member/relative/friends had cancer	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
Family tension due to long treatment	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	?
Symptom disclosure	Li et al. (2012)	Interviewer	New	–	–	–	–	–	–	↓
Social Factors (Role obligations, Symptom disclosure)	O'Mahony et al. (2013)	Self-administered questionnaire	Existing (Modified for study) (Facione et al., 2002)	✓	–	–	✓	–	–	↓[21]
Social Norm	Reifenstein (2007)	Self-administered questionnaire	Existing (Modified for study) (Lauver, 1994)	✓	✓	–	–	–	–	=

[21] Social factors of symptom disclosure to another person (OR = 0.24; $p < 0.001$) and 'not applicable' response to social constraints relating to family commitments (OR = 0.38; $p = 0.007$) associated with shorter TTP.

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Social network support for seeking medical attention	Unger-Saldana et al. (2012)	Interviewer	New	?	–	✓	✓	?	–	–

Table 19 Measure/items used for 'Social Factors'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Encouragement from others to see their GP	Bowen and Rayner (2002)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked whether they needed encouragement from a family member, or friend or colleague to see their GP
Knowledge of others with mammary tumours	Cameron and Hinton (1968)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Does breast cancer in a relative or friend affect delay?
Willingness to tell others about personal troubles	Cameron and Hinton (1968)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked whether there was an association between reluctance to tell others about personal troubles and delay.
Emotional Support	Cochran et al. (1986)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Emotional social support (Stewart, 1983, as cited in Cochran et al., 1983) was assessed by asking participants to rate how much emotional support they had received from each of 13 categories of people on 5-point scales. Included were spouses, medical professionals, neighbors, co-workers, family, and religious leaders.
Tangible Support	Cochran et al. (1986)	Tangible support (Schaefer et al., 1981) was measured using a 9-item Guttmann scale in which participants were asked, for example, if there was someone to whom they could go to get help with the housework or borrow money.
Marital Satisfaction	Cochran et al. (1986)	Measure used: "Dyadic Adjustment Scale" (Spanier, 1976) The "Dyadic Adjustment Scale" (Spanier, 1976) used to assesses marital satisfaction if married
Experience of mastectomy among family and friends	Greer (1974)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about their experience of

Psychosocial Factor	Author (Year)	How specific factors were assessed
		mastectomy among family and friends
Seeking advice	Hashim et al. (2010)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked if they sought advice: No one/Someone
Escorted by someone	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked if they were escorted by someone Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Any family member/relative/friends had cancer	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked if any family member/relative/friends had cancer Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Family tension due to long treatment	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about any family tension due to long treatment Response options: 1 ('no') to 5 ('completely agree')
Symptom disclosure	Li et al. (2012)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Women were asked whether they had disclosed to another the discovery of their symptom, and if so, to whom and when (Burgess et al., 1998)
Social Factors (Role obligations, Symptom disclosure)	O'Mahony et al. (2013)	Measure used: Modified version of "Constraint Scale" (Modified for study) (Facione et al., 2002) The following statements describe possible constraints to your visiting the GP when you found your breast symptom.

Psychosocial Factor	Author (Year)	How specific factors were assessed
		Please read each statement and indicate 'yes/no/not applicable' to indicate whether or not the statement relates to your own personal situation. 1) Taking care of my family (children / older relative) prevented me from going to the GP 2) Work commitments prevented me from going to the GP 3) I had nobody to talk to about the symptom 4) My spouse/ partner did not like me having my breasts examined by the GP
Social Norm	Reifenstein (2007)	Measure assessed participants' rating of perceptions of how much four different people (female friend, husband/partner, mother, and female relative) influenced their care-seeking behaviour (Lauver, 1994) Responses rated on four-point scale ranging from 1 ('not at all') to 4 ('extremely necessary')
Social network support for seeking medical attention	Unger-Saldana et al. (2012)	Who did you first talk to about your health problem? Name: _____ Relationship: _____ How long was there between you first noticing your discomfort and talking to the person named in the previous question? Answer in months or days, as answered by the woman □□ □□ Months Days (If respondent answers 'immediately' or 'very soon', input '0' days)

2.5.3.9 Coping Methods

i. Robustness of measures

The extent to which 'coping' affected actual TTP was assessed in seven studies (Forghieri et al., 2010; Hashim et al., 2010; Kumar et al., 2001; Prohaska et al., 1990; Reifenstein, 2007; Tromp et al., 2005; Unger-Saldana et al., 2012). All studies but one (Prohaska et al., 1990) mentioned some evidence of reliability or validity of the scale. **Table 20** documents the psychometric properties and TTP for 'Coping Methods', whereas **Table 21** documents the measure/items used for 'Coping Methods'.

Both Forghieri et al. (2010) and Reifenstein (2007) examined emotional coping using the "Ways of Coping Scale" (Folkman & Lazarus, 1988) which assesses thoughts and actions used to cope with stressful encounters of everyday living. Participants are given a wide range of thoughts and behaviours (e.g. 'I hoped for a miracle') and asked to rate their coping responses on a 4-point scale ranging from 'does not apply or not used' to 'used a great deal'. The scale has demonstrated good reliability with Cronbach's alpha ranging from $\alpha = 0.61$ to $\alpha = 0.79$ (Folkman & Lazarus, 1988).

Denial was measured by Reifenstein (2007) using a 9-item "Denial Scale" to assess the correlation of denial with days delayed in seeking care. Reliability of the scale was assessed in both the pilot (Cronbach's $\alpha = .88$) and actual study (Cronbach's $\alpha = .63$). Denial was also assessed with the 'Ways of Coping Questionnaire' (Folkman & Lazarus, 1988). Moreover, confrontive coping, social support strategies, and problem-solving strategies were assessed using the 'Ways of Coping Questionnaire' (Folkman & Lazarus, 1988). However, no correlation was found between the escape-avoidance subscale of the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1988) and the newly established 'Denial scale' when assessing construct validity of the newly established 'Denial scale'. Face validity of the scale was determined by a psychologist and a panel of nursing experts.

Kumar et al. (2001) examined domestic remedies/medicine before consulting a doctor. No details on the items were provided. Test-retest reliability was acceptable (ICC = 0.81).

Hashim et al. (2010) investigated self-treatment via a self-administered questionnaire. The authors did not provide further details on the items used, but noted that face validity was determined by a pre-test in six subjects. Further, the questionnaire was validated by an expert panel.

Coping styles as examined by a short version of the “Utrecht Coping List”, which measures active coping, seeking support, avoidance coping, palliative coping, and religious coping (Schreurs, Van de Willige, Brosschot, Tellegen, & Graus, 1993) were examined by Tromp et al. (2005). Tromp et al. (2005) did not provide any information on the number of items or psychometric properties of the scale. However, the original 44-item scale has demonstrated moderate to good internal consistency ($\alpha = 0.64$ to $\alpha = 0.82$) and reasonable test–retest reliability ($r = 0.52$ to $r = 0.79$) (Schreurs et al., 1993).

The usage of traditional or alternative medication was assessed by Unger-Saldana et al. (2012). Participants were asked ‘Have you taken or applied any home or alternative remedies for this health problem?’ (‘yes’ or ‘no’). Face and content validity of the entire questionnaire was assessed in the questionnaire development process but no reliability data was given for this specific question.

ii. Relationship with TTP

‘Coping methods’ were generally associated with longer TTP (Reifenstein, 2007; Tromp et al., 2005). Nevertheless, Reifenstein (2007) noted that for the 'Ways of Coping Questionnaire' (Folkman & Lazarus, 1988) only 'confrontive coping', 'seeking social support' and 'problem-solving' strategies were associated with shorter TTP, whilst there was no significant association between TTP and the other strategies. Both of these studies used scales with some evidence of reliability. A study by Kumar et al. (2001), which only had evidence of reliability found no link between ‘coping methods’ and TTP.

Table 20 Psychometric Properties and TTP for 'Coping Methods'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Ways of Coping	Forghieri et al. (2010)	Self-administered questionnaire	Existing (Folkman & Lazarus, 1988)	✓	–	–	–	–	–	–
Self-treatment	Hashim et al. (2010)	Self-administered questionnaire	New	–	–	✓	✓	–	–	–
Domestic remedies/medicine before consulting a doctor	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
*Illness behaviour*s (coping and self-help practices)	Prohaska et al. (1990)	Interviewer	New	–	–	–	–	–	–	–
Denial	Reifenstein (2007)	Self-administered questionnaire	New	✓	–	✓	–	?	–	↓ ↑[22] =
Coping Style	Tromp et al. (2005)	Self-administered questionnaire	Existing (Schreurs et al., 1993)	✓	✓	–	–	–	–	↑

[22] Regarding the 'Denial Scale' (Reifenstein, 2007) more denial (r = 0.36; p < 0.05) associated with longer TTP. Regarding the 'Ways of Coping Questionnaire' (Folkman & Lazarus, 1988) only 'confrontive coping' (r = -0.32; p < 0.05), 'seeking social support'(r = -0.37; p < 0.05), and 'problem-solving' (r = -0.32; p < 0.05) strategies associated with shorter TTP. 'Escape avoidance', 'distancing', 'self-controlling', 'accepting responsibility' and 'positive re-appraisal strategies' not significantly associated with TTP.

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Use of alternative medicine	Unger-Saldana et al. (2012)	Interviewer	New	–	–	✓	✓	–	–	–

Table 21 Measure/items used for 'Coping Methods'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Ways of Coping	Forghieri et al. (2010)	Measure used: "Ways of Coping Scale" (WCS) (Folkman & Lazarus, 1988) 36-item scale assessing thoughts and actions used to cope with stressful encounters of everyday living which gives the following subscale scores: planned problem solving, seeking social support , escape avoidance and their respective ratios
Self-treatment	Hashim et al. (2010)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about self-treatment (non-prescriptive/ traditional/ healing water/ homeopathy) Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Domestic remedies/medicine before consulting a doctor	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about domestic remedies/medicine before consulting a doctor Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
Illness behaviours (coping and self-help practices)	Prohaska et al. (1990)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* The use and type of over the counter medications taken in response to symptoms. Questions focused on over the counter medications concerning symptoms linked to colorectal cancer (antidiarrheal medications, laxatives, antacids, haemorrhoid ointments or suppositories, pain medications and other bowel medications
Denial	Reifenstein (2007)	Measure used: 9-item "Denial Scale" (Reifenstein, 2007) Only an example question was provided: ''Did you think that the breast change would disappear or go away?'' Response options: 5-point Likert-type scale was used with anchors from 0 (not at all certain) to 4 (most certainly). Scores could range from 0 to 36.
Coping Styles	Tromp et al. (2005)	Measure used: "Utrecht Coping List" (Short Version) (Schreurs et al., 1993)

Psychosocial Factor	Author (Year)	How specific factors were assessed
		17 items measuring coping styles. Five coping styles are distinguished: 1. Active coping (5 items) 2. Seeking support (5 items) 3. Avoidance coping (3 items) 4. Palliative coping (2 items) 5. Religious coping (2 items). Items are formulated as coping behaviours (e.g. "When facing a problem, I ask someone to help me") rated on a four-point Likert scale ranging from 1 ('seldom or never') 4 ('to quite often').
Use of alternative medicine	Unger-Saldana et al. (2012)	Have you taken or applied any home or alternative remedies for this health problem? Response options: yes/no

2.5.3.10 Spirituality and Religiousness

i. Robustness of measures

Three studies investigated how spirituality and religiousness affected TTP (Friedman et al., 2006; Gullatte et al., 2010; Kumar et al., 2001). **Table 22** documents the psychometric Properties and TTP for 'Spirituality and Religiousness', whereas **Table 23** documents the measure/items used for 'Spirituality and Religiousness'.

Two studies (Gullatte et al., 2010; Kumar et al., 2001) used a scale with some evidence of reliability and validity.

Gullatte et al. (2010) investigated how religious and spiritual beliefs influenced time to seek medical care and breast cancer stage. The authors measured spirituality, specifically an individual's reliance on a living relationship with God, using the 12-item Spiritual based coping subscale of the "Religious Coping Activity Scale" (RCAS) (Pargament et al., 1990), as well as three new items (1) 'in dealing with the problem, I was guided by God to wait'; 2) 'in dealing with the problem, I was guided by God to take care of it immediately, not wait'; 3) 'I trusted that my faith would see me through; when faced with a difficult problem, I just 'let go and let God.') on phrases spoken among African American women when describing their spiritual beliefs. Both the original subscale and the revised 15-item subscale have demonstrated good internal consistency reliability, as measured by Cronbach's alpha, $\alpha = 0.92$ and $\alpha = 0.85$ respectively. Further to this, religiosity was measured using the "Religious Problem Solving Scale" (RPSS) (Pargament et al., 1988). The scale aims to distinguish between the responsibilities individuals assign to themselves and to God, in addition to measuring the level of initiative taken by individuals in problem solving. Pargament et al. (1988) reported Cronbach's alphas for the subscales as collaborative $\alpha = 0.93$, self-directing $\alpha = 0.91$, and deferring $\alpha = 0.89$. In the reported study, the Cronbach's alpha for the total scale was $\alpha = 0.83$.

Kumar et al. (2001) examined patient's fate and god's destiny as part of a 60 item questionnaire. No details on the items were provided. Test-retest reliability of the whole questionnaire was examined in a sample of 10 participants over seven days. The reliability of the final questionnaire was acceptable (ICC = 0.81).

ii. Relationship with TTP

Friedman et al. (2006), who used a scale with no evidence of reliability or validity, noted a link between spirituality and TTP, specifically spirituality was linked to shorter TTP. Two studies (Gullatte et al., 2010; Kumar et al., 2001), which used scales with some evidence of reliability and validity found no link between 'spirituality and religiosity' and TTP.

Table 22 Psychometric Properties and TTP for 'Spirituality and Religiousness'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Spirituality	Friedman et al. (2006)	Self-administered questionnaire	New	–	–	–	–	–	–	↓
Spirituality	Gullatte et al. (2010)	Self-administered questionnaire	Existing (Modified for study) (Pargament et al., 1990)	✓	–	–	–	–	–	=
Religiosity	Gullatte et al. (2010)	Self-administered questionnaire	Existing (Pargament et al., 1988)	✓	✓	–	–	–	–	=
Patient's fate	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=
God's destiny	Kumar et al. (2001)	Self-administered questionnaire	New	–	✓	–	–	–	–	=

Table 23 Measure/items used for 'Spirituality and Religiosity'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Spirituality	Friedman et al. (2006)	How spiritual/religious do you consider yourself? Response options: Likert scale ranging from 1 ("not at all") to 5 ("very much")
Spirituality	Gullatte et al. (2010)	Measure used: "Religious Coping Activity Scale" (RCAS) (Modified for the study) (Pargament et al., 1990) For purposes of this study only the 12-item Spiritual-Based Coping subscale was used to measure an individuals' reliance on a living relationship with God. Gullatte et al. (2010) included three new or modified items on phrases often spoken among African American women when describing their spiritual beliefs with response options ranging from 1 ('not at all') to 4 ('a great deal'): a) in dealing with the problem, I was guided by God to wait; b) in dealing with the problem, I was guided by God to take care of it immediately, not wait; I trusted that my faith would see me through; c) when faced with a difficult problem, I just ''let go and let God.''
Religiosity	Gullatte et al. (2010)	Measure used: "Religious Problem Solving Scale" (RPSS) (Pargament et al., 1988) Scales measures religious problem solving designed to distinguish between the responsibility individuals assign to themselves and to God, as well as measure the level of initiative taken by individuals in problem solving The RPSS has three subscales (collaborative, self-directing and deferring) Response options: Likert scale ranging from 1 ('not at all') to 5 ('very much')
Patient's fate	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about patient's fate [also referred to as 'ill-fated to have cancer] Response options: Likert Scale ranging from 1 ('no') to 5 ('completely agree')
God's destiny	Kumar et al. (2001)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Patients were asked about god's destiny [also referred to as cancer as a curse]

Psychosocial Factor	Author (Year)	How specific factors were assessed
		Response options: Likert Scale ranging from 1 (‘no’) to 5 (‘completely agree’)

2.5.3.11 Health Values

i. Robustness of measures

Four studies investigated how health values affected TTP (Cameron & Hinton, 1968; Forghieri et al., 2010; Mansson et al., 1993; Tromp et al., 2005). **Table 24** documents the psychometric Properties and TTP for 'Health Values', whereas **Table 25** documents the measure/items used for 'Health Values'.

Two studies (Forghieri et al., 2010; Tromp et al., 2005) used a scale with some evidence of reliability and validity.

Forghieri et al. (2010) used the "Multidimensional Health Locus of Control Scale" (Form B) (Wallston, Wallston, & DeVellis, 1978) to determine health locus of control. The scale consists of 18-items to assess the perception of health control and consists of the three sections: internality powerful others and chance. Cronbach's alpha has been reported as 0.66 for internal health locus of control, $\alpha = 0.67$ for powerful others health locus of control and $\alpha = 0.58$ for chance health locus of control (Egan et al., 2009).

Health value and control beliefs were measured by Tromp et al. (2005) using the Dutch version of the "Revised Health Hardiness Inventory" (Gebhardt, van der Doef, & Paul, 2001). The authors did not provide any information on the questions or response options, but the scale consists of health belief statements that measure the extent to which individuals are committed to, and involved in, health-related activities, perceive health as controllable and approach potential health stressors as an opportunity for personal growth, with items measured on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5). Acceptable to adequate internal consistency has been reported for the subscales: $\alpha = 0.74$ (health value), $\alpha = 0.62$ (internal locus of control), $\alpha = 0.59$ (external locus of control) and $\alpha = 0.59$ (perceived health competence).

ii. Relationship with TTP

Two studies (Cameron & Hinton, 1968; Mansson et al., 1993) found no association between TTP and 'Health values'. Neither of these studies used a scale with some evidence of reliability or validity.

Table 24 Psychometric Properties and TTP for 'Health Values'

Psychosocial Factor	Author (Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Habitual concern over health	Cameron and Hinton (1968)	Self-administered questionnaire	New	–	–	–	–	–	–	=
Health Locus of Control	Forghieri et al. (2010)	Self-administered questionnaire	Existing	✓	–	–	–	–	–	–
Habitual perception of bodily changes	Mansson et al. (1993)	Self-administered questionnaire	New	–	–	–	–	–	–	=
Health Value and control beliefs	Tromp et al. (2005)	Self-administered questionnaire	Existing (Modified for study) (Gebhardt et al., 2001)	✓	–	–	–	–	–	–

Table 25 Measure/items used for 'Health Values'

Psychosocial Factor	Author (Year)	How specific factors were assessed
Habitual concern over health	Cameron and Hinton (1968)	Do you usually worry about your health? a) very rarely b) rarely c) sometimes d) often e) very often
Health Locus of Control	Forghieri et al. (2010)	Measure used: "Multidimensional Health Locus of Control Scale" (MHLC; Form B) (Wallston et al., 1978) 18-item scale used to assess the perception of health control and structured into three dimensions: internality, powerful others and chance.
Habitual perception of bodily changes	Mansson et al. (1993)	*[Details of measure and/or items not provided. Measure and/or items assessed the following variables as extracted from the results section]* Perception of bodily health and function: a) any change more or less acutely noticed b) minor changes not noticed
Health Value and control beliefs	Tromp et al. (2005)	Measure used: Revised version of the "Health Hardiness Inventory" (Gebhardt et al., 2001) Scale contains health belief statements concerning four scales: 1. Health value (six items, e.g. I take care of my health as a matter of principle) 2. Internal locus of control (five items, e.g. "The main thing that affects my health is what I do myself") 3. External locus of control (seven items, e.g. "No matter what I do, if I am going to get ill, I will get ill") 4. Perceived health competence (six items of eight items of original Perceived Health Competence Scale, Smith, 1995) Response options: Likert scale ranging from 1 ('not at all') to 5 ('very much')

2.6 Discussion

2.6.1 Principal findings

This is the first systematic literature review examining the robustness with which psychosocial factors that may affect TTP for symptoms of cancer are quantitatively measured. The vast majority of studies failed to report the use of valid and reliable measures. The measurement tools available to understand influences on help-seeking behaviour and to measure the impact of interventions to encourage early diagnosis are limited. It is not necessarily the case that the measures are not valid or reliable of course, but at present little formal psychometric testing appears to have been conducted and thus the robustness and trustworthiness of these instruments is unknown. The synthesis shows that the relationship between psychosocial factors and TTP is mixed, and this finding may be due to use of measures which are not robust.

This systematic review has highlighted that when no or minimal validity or reliability evidence was present, results were inconclusive or differed to those studies which used reliable and valid measures (particularly the case for reasons for help-seeking, risk perception, spirituality and religiosity, health values, access to healthcare, knowledge, social factors and coping methods). For some psychosocial factors (e.g. reasons for delay, symptom interpretation) the lack of psychometrically tested measures prevented clear conclusions to be made about the results of the study related to the quality of the measures. For measures of emotion, the specific emotion being measured, rather than the measure itself appeared to impact the results.

2.6.2 Strengths and limitations

Even though five existing systematic reviews (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999) previously investigated factors influencing delay in a range of cancers, this the first review of worldwide literature that has examined how contributing psychosocial factors that affect TTP for [potential] symptoms of cancer were measured.

The main strengths of this review were the systematic nature of the search for literature across five databases (medical, psychological and social scientific) and the use of the five existing systematic reviews (Macdonald et al., 2006; Macdonald et al., 2004; Mitchell et al., 2007; Ramirez et al., 1999; Richards et al., 1999). An additional strength of this review is

the inclusion of studies in any language, reducing the potential for bias introduced by the exclusion of papers published in non-English language journals.

Nevertheless, this review may be subject to limitations. The coverage of various fields may also pose a disadvantage to the current research. Publications in this area are spread over many journals across different fields, and it is possible that some articles were overlooked through variable indexing and use of subject headings. There may also be evidence of reliability or validity of some of the existing scales when used in non-cancer contexts that has been missed. Furthermore, Macdonald et al's (2004) systematic review of the literature from the pre 1970s to November 2003 to identify factors influencing patient and primary care delay in the diagnosis of cancer excluded breast cancer at the request of the Department of Health, because Richards et al. (1999) performed a systematic search on factors influencing delay in breast cancer from 1966 to 1999. Given that no systematic search on factors influencing help-seeking for breast cancer was conducted for four years, it may be that publications pertaining to breast cancer were overlooked.

2.6.3 Methodological issues in existing research

The availability of reported psychometric properties of measures varied between the different types of psychosocial factors. The proportion of measures with any form of assessment of reliability or validity was as follows: 0% for risk perception, 18% (3 out of 17) for 'reasons for delay', 22% (4 out of 18) for symptom interpretation, 33% (2 out of 6) for 'reasons for seeking help', 38% (3 out of 8) for knowledge, 50% (8 out of 16) for emotional response, 50% for health values (2 out of 4), 55% (6 out of 11) for access to healthcare, 60% (9 out of 15) for social factors, 67% (2 out of 3) for spirituality and religiosity and 86% (6 out of 7) for coping methods. In many cases, only one form of validity or reliability was assessed. Overall, when reliability or validity of measures were tested this was often only cursory. For example, in terms of reliability, if it was established, the main type reported was internal consistency, and this was not common in newly developed measures. The most commonly reported forms of validity were face validity and content validity, but most new scales were not tested for either form.

This review did not critically assess the quality of the psychometric testing. Further investigation of the methods used to establish reliability and validity is likely to reveal further weaknesses in the strength of the evidence of some claims of reliability and validity in this area.

With regard to validity, important information was often very limited. For example, the methods for item generation or selection, item reduction, and the execution of a pilot study to examine the adequacy and feasibility of research instruments was only justified and reported in three studies (O'Mahony & Hegarty, 2009; Reifenstein, 2007; Unger-Saldana et al., 2012). The remainder of the studies did not provide further details on this. Therefore, it can be argued that the items used to assess the contributing psychosocial factors that affect TTP for [potential] symptoms of cancer fail to comprehensively represent all issues that are important to the target population.

Consequently, more attention must be given to not only when designing studies, but also to how items are created. Regardless of whether items are generated through an inductive or deductive process there should be a significant link between a theoretical domain and items. This can be accomplished by commencing with a theoretical framework and using a rigorous sorting process where items are matched to construct definitions. Even though it would seem that theoretical frameworks are a prerequisite when designing research or measures on symptom appraisal or help-seeking behaviour, only few studies used theoretical models to guide study design or measurement construction. Only six studies (Andersen et al., 1995; Friedman et al., 2006; O'Mahony et al., 2013; Reifenstein, 2007; Ristvedt & Trinkaus, 2005; Scott et al., 2008) used components of theoretical models as well as other variables to guide the study design and therefore provide a theoretically guided insight into patient delay. Another three authors noted that they based their questionnaire on anecdotal knowledge, qualitative interviews with (breast cancer) patients and a review of the literature (O'Mahony & Hegarty, 2009; Reifenstein, 2007; Unger-Saldana et al., 2012), whereas only one study seemingly based their questionnaires on a theoretical domain (Kumar et al., 2001). However, designing studies or developing measures that are not guided by a theoretical model is potentially problematic as it may have caused researchers to choose factors that may have had little or no effect, or it could miss out crucial factors.

2.6.4 Conclusion and implications for subsequent studies

The review highlighted numerous methodological and design issues regarding how psychosocial factors influencing help-seeking behaviour are measured. Most studies developed new items or scales, yet more attention must be given to how scales or items are developed and how robust the new measures are. The use of measurements that lack

reliability or validity may impede the conclusions drawn from the study. If an invalid measure is used then inaccurate assumptions may be made.

Consequently, to improve the methodological quality of future studies that assess how psychosocial factors influence TTP for symptoms of cancer it is recommended that:

- Prior to item development the purpose, objectives, research questions, and hypothesis of the proposed research should be determined;
- Researchers should use existing measures that display adequate reliability or validity rather than developing new measures. For example, measures used by O'Mahony et al. (2013) to assess access to healthcare, social factors, emotional response to symptoms, beliefs about symptoms, and knowledge of breast cancer, and measures used by Unger-Saldana et al. (2012) to assess perceived seriousness of symptoms and perceived reasons for delay each had evidence of both reliability and validity. However, it should be noted that the measure by Unger-Saldana et al. (2012) is currently only available in Spanish and would need to be translated into English and then undergo further testing to achieve equivalence between the original version and the translated version (Streiner et al., 2015);
- Overall, there is an overall lack of psychometrically sound measures, especially for barriers to seeking help, symptom interpretation and risk perception in this context, and thus new measures may be needed for these factors;
- If researchers develop new measures, item development should be based on a deductive or inductive approach and guided by numerous sources, such as interviews, observations, expert opinion, theory and/or existing research;
- Once measures have been developed they should be assessed for both reliability and validity with sound psychometric testing.

Chapter 3 : A secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms: Applying the Model of Pathways to Treatment.

3.1 Introduction

This chapter describes a secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms. Data from four existing qualitative studies carried out in the UK and Australia that examined the appraisal and help-seeking behaviour of people with [potential] symptoms of cancer were analysed and classified according to contributing factors (constructs of the CSM) (Leventhal et al., 1984) to the appraisal interval of the MPT (Scott et al., 2013).

The introduction of this chapter describes how the CSM can help to identify the 'contributing factors' within the appraisal interval in the MPT by further describing the various stages within the CSM and highlighting how the CSM has been applied in research to date.

This chapter and the remainder of the thesis will focus on the 'appraisal' interval of the MPT. A focus on the 'appraisal' interval was chosen as symptom appraisal is a key determinant of delay and accounts for the majority of the patient interval as evidenced by Andersen et al. (1995). The length (in days) of the four delay stages was investigated for subjects diagnosed with gynaecological and breast cancer to obtain a total measure of delay. For gynaecological cancer appraisal accounted for 80% of the TTP, whereas for breast cancer it accounted for 60% (Andersen et al., 1995).

3.2 Background

3.2.1 Theoretical Issues

Walter et al. (2012) and Scott et al. (2013) proposed the MPT. Specifically, within the MPT (Scott et al., 2013), existing theoretical models, such as the CSM (Leventhal et al., 1984) can help to identify the 'contributing factors' within the appraisal interval (see **Figure 4**).

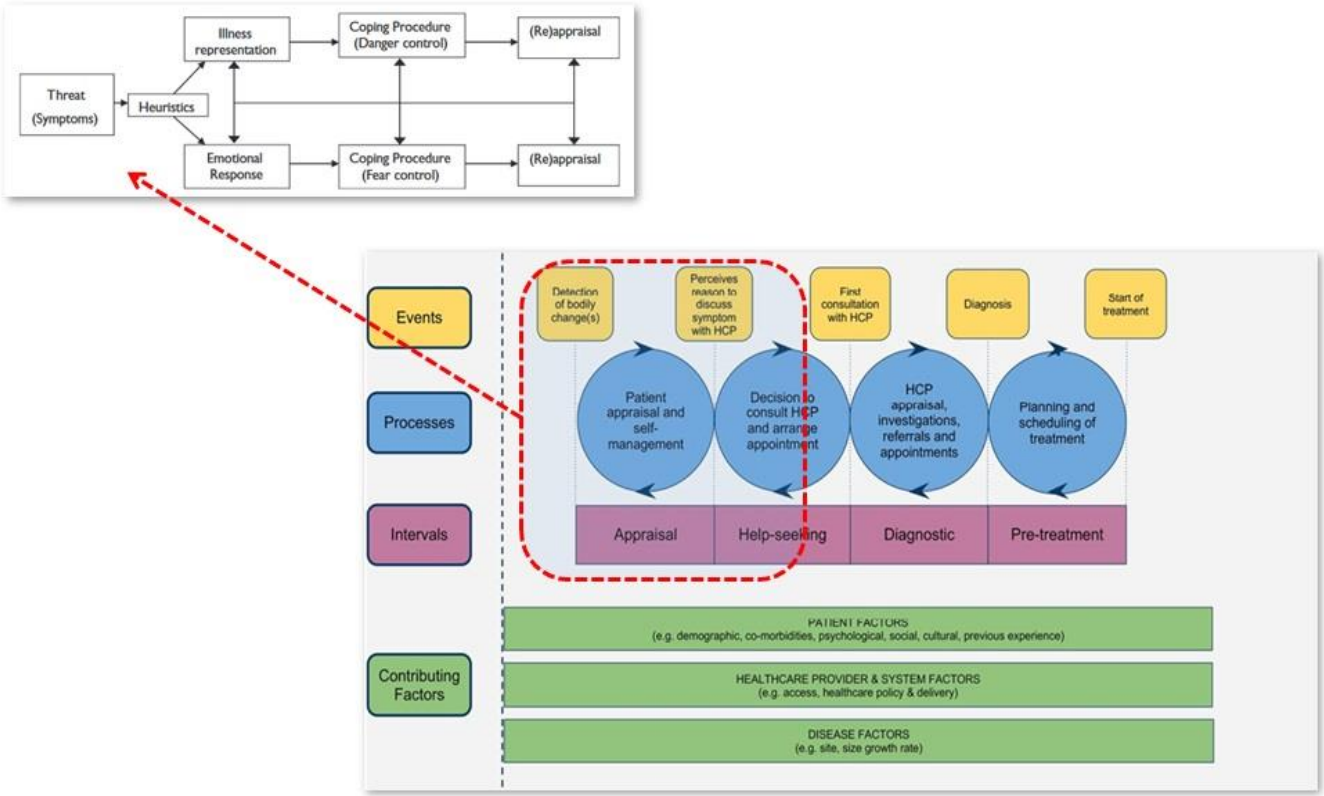

Figure 4 Model of Pathways to Treatment and Common Sense Model of Illness Self-Regulation (Leventhal et al., 1984; Scott et al., 2013)[23]

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3.2.1.1 Common Sense Model of Illness Self-Regulation: Theoretical Background

The CSM (Leventhal et al., 1984) is a theoretical model which illustrates how individuals interpret and cope with health threats. According to Leventhal, Meyer, and Nerenz (1980) the CSM can be regarded as a parallel process model that encompasses two motivational systems: a cognitive and an emotional system.

3.2.1.1.1 The Cognitive System

The cognitive system helps individuals to establish illness beliefs or schemas of their health threat. Illness representations are defined as a set of beliefs concerning how illness affects the body and the possible consequences on activities and experiences. According to the CSM there are five components of illness representations: 1) identity [beliefs about the symptoms associated with the illness and of the labels associated with the illness], 2) cause [factors believed to have triggered the illness], 3) timeline [expected duration of the illness], 4) consequences [expected severity of the illness and the effects of the illness on physical, social, and psychological wellbeing] and 5) cure/control [extent to which the illness can be controlled or cured with treatment]. Subsequently, 'coherence' [whether a person has a coherent understanding of the illness] has been suggested to be a sixth component (Moss-Morris et al., 2002). Individuals develop illness representations based upon three elements: 1) lay knowledge about a health threat or an illness, 2) current and previous experience of illness of oneself and others and 3) knowledge obtained via external sources of information such as health professionals (Leventhal et al., 1980; Leventhal et al., 1984). When an individual experiences a bodily change they will search their semantic memory for abstract information (what is expected according to schema) in order to match their symptoms (concrete information) with existing labels or diagnoses (Cameron & Moss-Morris, 2004; Hagger & Orbell, 2003).

For bodily changes to be perceived as a symptom, they must be unexpected and exceed an inference threshold. Bodily changes below the threshold tend to be normalised (Leventhal, Brisette, & Leventhal, 2003). To help interpret symptoms individuals rely on cognitive heuristics, or so called rules of thumb. With regard to the CSM, Leventhal and colleagues (Leventhal, Forster, & Leventhal, 2007) have identified numerous heuristics that individuals might use to form a representation about their symptoms and decide whether symptoms require medical care (see **Table 26** for definitions of heuristics). The notion of heuristics was first proposed by Tversky and Kahneman (1974). Heuristics are defined as logical

shortcuts that are used to condense difficult mental operations to simpler cognitive tasks (Kahneman, Slovic, & Tversky, 1982). Tversky and Kahneman (1974) originally suggested that individuals use three heuristics consciously or unconsciously in order to arrive at a decision:

1. *Availability*. The likelihood of an event is judged by the ease with which an occurrence first comes to mind;
2. *Representativeness*. As long as A is significantly similar to B, the likelihood that A belongs to B is judged to be high. If A is not similar to B then the likelihood that A belongs to B is low;
3. *Anchoring and Adjustment.* Estimating the likelihood of an event starts at an initial point. The initial point will be adjusted upon receiving further information. Final appraisals tend to be biased towards the initial starting point.

However, to date there has been a lack of studies that have provided insight into how or whether heuristics underlie symptom appraisal for symptoms of cancer.

Table 26 Definitions of heuristics influencing the interpretation of symptoms as outlined by Scott et al. (2013)

Heuristic	Definition
Symmetry rule	There is a bi-directional relationship between symptoms and labels in that experiencing symptoms leads to a search for an illness label and illness labels produce an expectation of symptoms.
Location rule	The area of the body in which symptoms arise influences their interpretation (e.g., oral pain is 'toothache', and breathlessness is connected to the lungs (rather than the heart).
Pattern rule	Diffuse, ambiguous symptoms lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Such symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care
Rate of change rule	Those symptoms that are worsening, unstable, or increasing in number, and symptoms that have a sudden rather than gradual onset, can indicate illness and provide motivation to seek help promptly
Severity rule	Symptoms that are extreme or 'severe' (rather than mild or vague) and disrupt functioning indicate the need for care.
Novelty rule	Symptoms that are new, different, or incongruent (unexpected) with underlying schema rather than familiar, common, or similar to a co-existing chronic illness can be a key motivator to seek help
Duration rule	Symptoms that are persistent or prolonged (compared to previous experience or expectations), rather than short lived or intermittent, can indicate a level of seriousness, which in turn, can be a reason for urgently seeking help.
Age-illness rule	As individuals grow older, they increasingly attribute sensations to the ageing process rather than to illness.
Stress-illness rule	Ambiguous symptoms are often discounted during times of acute stress and are more likely to be attributed to stress rather than physical illness.
Optimistic bias	Individuals have a generally optimistic bias in that their interpretations, in keeping with previous experience, and will tend to make innocuous explanations rather than those that are life threatening.
Prevalence rule	Symptoms that are perceived to be prevalent in the community are more likely to be considered less threatening (i.e., minor rather than serious). Conversely, symptoms that are seen to be rare are more likely to invoke concern and act as a motivator to seek help.
Similarity rule	Perceived susceptibility or vulnerability to illness can emerge from perceived similarity in exposure, temperament, physical characteristics between the self and those with a certain illness and this in turn can influence symptom interpretation.

According to the CSM (Leventhal et al., 1984), the attributes of illness representations will determine the selection and performance of coping procedures. Coping procedures are defined as the actions taken to preventing, treating and overcoming somatic changes. If somatic changes are believed to be a minor condition (e.g. a headache), there will usually be a tendency to wait and see what happens (e.g. symptom monitoring), or a specific action may be chosen (e.g. taking medication). If somatic changes are believed to be serious, then action(s) to control and eliminate the threat may involve seeking medical care. Ultimately, the type of coping procedure chosen depends on the representation of the problem. Coping procedures are also a part of so-called 'if-then' rules. 'If-then' rules connect symptom representations with plans that are currently accessible to an individual. Leventhal, Leventhal and Contrada (1998) define the 'if' aspect as the interpretation of a health threat, whereas the 'then' aspect is the action that will be taken given a particular situation. Such 'if-then' rules have been suggested to be a good indicator of subsequent help-seeking behaviour (Martin, Rothrock, Leventhal, & Leventhal, 2003).

3.2.1.1.2 The Emotional System

Parallel to the cognitive level, health threats will activate an emotional system which will cause an emotional response. For example, Cameron and Moss-Morris (2004) who suggested that discovering a breast lump could cause a fear response and the trigger of an illness representation (e.g. cancer) will lead to an emotional response, which in turn will lead to the selection and use of coping behaviours to control such emotions.

It is plausible that different emotions play different roles at different times prior to presentation to a HCP. In support of this, a systematic review reported that emotion in response to discovery of potential symptoms (e.g. fear, anxiety, concern) has been found to be associated with shorter TTP. However, the same review found that emotions specific to consequences of seeking help may act as a barrier to seeking help (Balasooriya-Smeekens et al., 2015).

3.2.1.2 The Common Sense Model of Illness Self-Regulation: Empirical Evidence

The CSM has been widely applied across different diseases and response to diseases. Questionnaires designed to assess each of the five illness representations components as illustrated in the CSM, known as the IPQ (Weinman et al., 1996) and the revised IPQ (IPQ-R) (Moss-Morris et al., 2002) have for example been used to determine the relationship between illness perceptions and adherence to asthma medication (Byer & Myers, 2000;

Horne & Weinman, 2002; Ohm & Aaronson, 2006), illness perceptions and self-care behaviours in diabetes (Abraham, Sudhir, Philip, & Bantwal, 2015; French, Wade, & Farmer, 2013; Louise, Stephen, & Deborah, 2016; van Puffelen et al., 2015) or illness perceptions and coping in individuals with rheumatoid arthritis (Carlisle, John, Fife-Schaw, & Lloyd, 2005; Murphy, Dickens, Creed, & Bernstein, 1999; Scharloo et al., 1998).

With regard to help-seeking behaviour, the CSM (Leventhal et al., 1984), for instance, has been used to understand the relationship between symptom representations and help-seeking among patients with heart failure.

For example, a study that evaluated the ability of the CSM to explain the factors influencing the decision to seek treatment for symptoms of acute myocardial infarction in a sample of 61 men and women showed that gender significantly predicted TTP with females having a longer TTP than males. Further, men who thought a heart attack would have serious consequences and who engaged in active-cognitive and problem focused coping behaviour were quicker to seek help (Walsh, Lynch, Murphy, & Daly, 2004).

MacInnes (2014) explored illness and treatment beliefs in patients with heart failure. Illness representations as outlined in the CSM were used for the qualitative interview schedule. Findings showed that patients were unable to differentiate heart failure from other symptoms. Furthermore, heart failure was sought to be caused by external factors or through stressful life events, and frequently regarded as a chronic condition which could only be controlled by medication. Similarly, another study that applied the CSM to investigate delay in seeking care for AMI symptoms revealed that patients who believed that their symptoms were caused by their heart were more likely to believe that there would be consequences of symptoms if help-seeking was delayed Quinn (2005).

Moreover, McCabe, Chamberlain, Rhudy, and DeVon (2016) who asked women to label the type and duration of symptoms, perceived cause, seriousness, controllability and symptom response prior to being diagnosed with atrial fibrillation noted that individuals did not think their symptoms were caused by a disease, failed to interpret their symptoms as serious and believed they could be easily controlled by medications. The vast majority of participants in this study had a wait and see approach, on average waiting over a week to seek treatment once noticing symptoms.

Beal (2014) used the CSM as a conceptual framework to study how cognitive and behavioural responses to symptoms of acute ischemic stroke differed between women who went to the hospital within three hours of noticing symptoms and those who went

three hours after symptom onset. It was found that the majority of patients failed to recognise the cause of symptoms. Further, there was a lack of knowledge in relation to treatment of stroke as well as a lack of perceived susceptibility despite being at risk of acute ischemic stroke.

Although the CSM (Leventhal et al., 1984) has been applied to determine help-seeking behaviour in heart failure studies, little is known about how components of the model influence symptom interpretation and response for cancer symptoms, and subsequent medical care seeking. So far, relatively few studies have used components of the CSM (Leventhal et al., 1984) to examine or explain help-seeking intentions among individuals with cancer symptoms.

Hunter, Grunfeld, and Ramirez (2003) looked at help-seeking intentions for hypothetical breast cancer symptoms using questionnaire items encompassing components of the CSM and the Theory of Planned Behaviour (Ajzen, 1991). Findings showed that identity was a strong predictor of help-seeking intentions, whereas time-line, consequences and control/cure beliefs were not a significant predictor. However, as this study was hypothetical a comparison to affective responses cannot be made and its applicability to actual responses is unknown.

A modified version of the IPQ-R (Moss-Morris et al., 2002) was used to examine the relationship between emotional and cognitive symptom representations prior to diagnosis for colorectal cancer symptoms (Jensen, Hvidberg, Pedersen, & Vedsted, 2015). Cognitive symptom representations (specifically treatment control and timeline cyclical dimension) were linked to delayed help-seeking. Further, results from this study showed a significant interaction between cognitive symptom representations of consequences and personal control in patients who identified blood in their stool as the most important symptom.

Similarly, O'Mahony et al. (2013) examined women's help seeking behaviour and factors linked to self-discovery of symptoms upon their first visit to the clinic and prior to their initial assessment by the medical team. The IPQ (Weinman et al., 1996) was modified for this study to examine women's beliefs about their breast symptoms. No significant relationship was found between beliefs concerning symptom cause, cure/control, consequences, outcome and help seeking behaviour. A significant relationship was only found between beliefs concerning symptom duration and help seeking behaviour, specifically those who delayed had higher scores on duration, suggesting that they perceived their symptom to last longer.

Even though the CSM (Leventhal et al., 1984) has only been explicitly applied in a small number of studies exploring the factors contributing to delayed presentation for cancer symptoms, (components of) the model could be used to further explain the findings from existing research. For example, a study that examined women's interpretation of, and responses to, potential gynaecological cancer symptoms showed that women frequently attributed their symptoms to an existing or previous illness, disease, surgery or injury, therefore suggesting that women will try and fit new symptoms to an existing illness schema (Low et al, 2015). Conversely, when symptoms are different to the preconceived expectation about an illness then help-seeking may be less likely: only a minority of people noticed a match between their observed skin changes and their mental image of a melanoma (Walter et al., 2014). The majority of participants in this study reported that their observed skin changes did not match their mental image and as such people appeared more likely to 'normalise' their skin changes, or adopt other explanations, thus delaying help seeking and diagnosis.

In support of how giving meaning to an illness will determine coping behaviours, research examining the causes associated with longer TTP suggests that denial of the seriousness of symptoms or ignoring symptoms (Grant, Silver, Bauld, Day, & Warnakulasuriya, 2010; Lam et al., 2009; Macleod et al., 2009; Molassiotis et al., 2010; Nosarti et al., 2000; O'Mahony, Hegarty, & McCarthy, 2011; Salander, Bergenheim, Hamberg, & Henriksson, 1999), adaptations to lifestyle (Molassiotis et al., 2010), symptom monitoring (Lam et al., 2009; Molassiotis et al., 2010), as well as the use of self-managing techniques or self-medicating (Birt et al., 2014; Emery et al., 2013a; Grant et al., 2010) may be a determinant of longer TTP.

3.3 Aims and Objectives

Few studies have applied the CSM to identify and explore factors that influence timely presentation for symptoms of cancer. Furthermore, existing studies have usually only considered one element of the CSM (e.g. illness perceptions), rather than all the constructs of the CSM. The aim of this study was to explore the contributing factors of patients' appraisal of symptoms that are documented in existing qualitative data. In pursuit of this aim, the study examined whether responses given by interviewees could be classified according to contributing factors (constructs of the CSM) within the appraisal interval of the MPT (Scott et al., 2013) (**Figure 4**). In addition to testing the validity of the MPT (Scott

et al., 2013), classifying the responses according to the contributing factors would allow insight into which contributing factors are most prominent in the accounts of appraisal, and help to identify the ways in which each factor is referred to; the latter of which ultimately helped to generate items for the PaTH-Q.

3.4 Methods

This study involved a secondary analysis of qualitative data from four studies undertaken in the UK and Australia, which each examined the appraisal and help-seeking behaviour of people with symptoms, or potential symptoms, of cancer. Data selection and analysis were underpinned by the theoretical approach of the MPT. Ethical approval for this study was covered by the ethical approval obtained by the relevant PIs (SS, FW and JE) for the individual studies.

3.4.1 Secondary Data Analysis of Existing Qualitative Data

Secondary analysis of qualitative data encompasses the use of existing data to answer research questions that differ from the questions explored in the original research (Hinds, Vogel, & Clarke-Steffen, 1997). The advantages of performing a secondary analysis of existing qualitative data have been highlighted by numerous researchers (Hinds et al., 1997; Sandelowski, 1997; Szabo & Strang, 1997; Thorne, 1994). For example, Heaton (1998) acknowledged that secondary analysis can provide support for existing theories or enable new hypotheses or information to be established.

To date, secondary analysis has mostly been applied in situations where researchers wanted to 1) carry out additional analyses of an original dataset, 2) conduct further analyses of a sub-set of the original dataset, or 3) refine the study purpose, questions and data collection processes (Hinds et al., 1997). Even though secondary analysis of qualitative data is becoming more prevalent, comparatively few studies or methodology papers exist that explain the types of analyses and procedures involved.

Researchers have suggested that before a secondary analysis is performed numerous factors should be considered (Heaton, 1998; Thorne, 1994). First, the compatibility between the datasets and the secondary research questions(s) should be ensured. Second, it is recommended that the research questions for the secondary analysis are similar to the original research questions. Third, data collection and analyses procedures utilised in the original study should be similar to the process that will be implemented in the secondary

analysis. Fourth, the quality of the primary dataset and whether the dataset is likely to answer the questions of the secondary research should be assessed. Quality of the data can be assessed through a pilot study, examining the credentials of the original study team or through using an assessment tool (Hinds et al., 1997). An assessment tool was developed by Hinds et al. (1997). The tool assesses the accessibility, quality, completeness and fit of datasets, in addition to determining the re-usability of datasets collected by other researchers. Assessing the quality of data also enhances the likelihood that data sets are appropriate and adequate (Charmaz, 2006). Fifth, researchers should decide whether original datasets are still current and whether the timing of the secondary analysis is appropriate (Hinds et al., 1997).

Further to this, Heaton (1998) suggests that the original study, data collection procedures and analyses processes should be outlined by researchers. The purpose of the secondary analysis should also be transparent, specifying methodological and ethical concerns, and any decisions made regarding missing data. Moreover, it is crucial to document the actual process in detail, including methods for re-using different kinds and sources of data for different purposes, and if and how informed consent has been obtained for secondary studies (Heaton, 2004).

Whereas some researchers (Corti & Thompson, 1998; Glaser, 1963; Heaton, 1998; Hinds et al., 1997; Thorne, 1994) encourage secondary analysis, others have expressed a number of practical and ethical concerns (Hinds et al., 1997; Mauthner, Parry, & Backett-Milburn, 1998; Szabo & Strang, 1997; Thorne, 1994). According to Mauthner et al. (1998) the relevant context that is required to interpret interview transcripts can only be thoroughly understood if researchers were actually involved in the data collection process. Another concern is whether data should be re-used for purposes other than which it was collected for (Heaton, 1998).

3.4.1.1 Description of Data Sources

Data were obtained from the following four studies:

1. The Melanoma Interview Study (Walter et al., 2014)
2. The SYMPTOM study (Banks et al., 2014; Birt et al., 2014; Hall et al., 2015; Mills et al., n.d.; Walter et al., 2014)
3. Improving Rural Cancer Outcomes (IRCO) (Emery et al., 2013a; Emery et al., 2013b)

4. Patient delay in oral cancer: a qualitative study of patients' experiences (Scott, Grunfeld, Main & McGurk, 2006)

The details of each study are outlined in **Table 27**.

Table 27 Description of data source

Data source	Study Description	Inclusion criteria	Country	Cancer type	Number of transcripts obtained
The Melanoma Interview Study (Walter et al., 2014)	The study aimed to determine how people detect skin symptoms and signs, their decisions to seek help, and their experiences preceding their diagnosis with melanoma via in-depth interviews. A purposive sampling strategy across two regions was used (South Eastern Scotland and Eastern England) to sample as wide a range of characteristics of a population as possible (melanoma thickness, age, gender and education level). Participants underwent in-depth interviews within 10 weeks of being informed of their diagnosis.	Adults aged 18 and above who were newly diagnosed with a primary invasive cutaneous melanoma [staged as < 1mm (T1,'thinner') or ≥ 2 mm (T3 and T4, 'thicker'].	United Kingdom	Melanoma	8
The SYMPTOM study (Banks et al., 2014; Birt et al., 2014; Hall et al., 2015; Mills et al., n.d.; Walter et al., 2014)	The study aimed to determine factors influencing symptom appraisal and help-seeking in people referred with symptoms suspicious of pancreatic, colorectal and lung cancer. Patients were recruited purposively	Adults aged 40 years and over who were referred to hospital via urgent (two week wait), routine and diagnostic routes, for	United Kingdom	Pancreas Colorectal Lung	8 7 8

Data source	Study Description	Inclusion criteria	Country	Cancer type	Number of transcripts obtained
	from two regions (East and North-east of England).	whom GPs had reported symptoms possibly suggestive of pancreatic, colorectal and lung cancer.			
Improving Rural Cancer Outcomes (IRCO) (Emery et al., 2013a; Emery et al., 2013b)	The study explored factors influencing treatment delay which could adversely impact outcomes in rural cancer patients in Western Australia, in addition to determining patient decision-making about symptom appraisal and help-seeking.	Patients were eligible if they lived rurally (in either the Goldfields or the Great Southern regions of Western Australia), and had recently been diagnosed with prostate, breast, colorectal or lung cancer. [N.B. Only data from breast and prostate cancer patients were obtained for the current study as data on colorectal and lung cancer were obtained from the	Australia	Breast Prostate	5 5

Data source	Study Description	Inclusion criteria	Country	Cancer type	Number of transcripts obtained
		SYMPTOM study].			
Patient delay in oral cancer: a qualitative study of patients' experiences (Scott, Grunfeld, Main & McGurk, 2006)	The study determined patients' understanding of oral cancer symptoms and to investigate their decision to seek help for these symptoms. Patients who had received a diagnosis of oral squamous cell carcinoma were asked to complete in-depth semi-structured interviews.	Adults aged 18 and over who were able to speak English, diagnosed with squamous cell carcinoma of the oral cavity and who had not yet started treatment.	United Kingdom	Oral	9

3.4.1.2 Selection criteria

Principal Investigators (PIs) from the Melanoma Interview Study (Walter et al., 2014), the 'SYMPTOM study' (Banks et al., 2014; Birt et al., 2014; Hall et al., 2015; Mills et al., n.d.; Walter et al., 2014), the 'IRCO' study (Emery et al., 2013a, 2013b) and the 'Patient delay in oral cancer study' (Scott, Grunfeld, Main, & McGurk, 2006) were contacted and asked to provide six anonymous interviews from each cancer type according to the following criteria:

- Two patients from the dataset who had the longest TTP. One of these patients should be aged under 60 and the other above 60.
- Two patients from each dataset who had the shortest TTP. One of these patients should be aged under 60 and the other above 60.
- Two patients from each dataset who were around the median TTP. One of these patients should be aged under 60 and the other above 60.

With regard to age and gender, an equal variation was sought. If it was not possible to obtain an equal variation of age and gender for the short and long TTP group, principal

investigators of the respective studies were contacted again to request additional transcripts with the sought after criteria.

After analysis of the initial datasets it was decided to analyse two additional transcripts from each cancer type to increase the amount of data available for analysis. Therefore the PIs were contacted again and asked to select a further two interviews from each cancer type according to the following criteria:

- Patients who had the third longest and third shortest TTP irrespective of their age and gender.

3.4.2 Data Analysis

Data were analysed using a directed approach to content analysis (Hsieh & Shannon, 2005). This approach is frequently utilised to validate a theoretical framework or theory (Marshall & Rossman, 1995). In directed content analysis, existing theory or research is used to help identify key concepts or variables as initial coding categories (Potter & Levine-Donnerstein, 1999). Next, definitions for each category are obtained using key concepts or variables outlined in a theoretical framework.

To help code data for this study, a structured categorisation matrix was developed by SK in collaboration with SS and FW (see **Table 28** and **Table 29**). The categorisation matrix was based on the contributing factors outlined [constructs of the CSM (Leventhal et al., 1984) and the SCT (Bandura, 1986, 1997)] within the appraisal and help-seeking interval of the MPT (**Figure 4**) (Scott et al., 2013; Walter et al., 2012) which served as an initial theoretical framework to help ascertain key variables or concepts as initial coding categories.

Following this, all transcripts were reviewed carefully by SK, highlighting all text that appeared to describe the factors that contribute to patients' appraisal of symptoms and decision to seek help. Throughout the analysis process SK also actively searched for text that was contradictory to each heuristic as well as that which supported a heuristic. All highlighted text was coded using the predetermined categories wherever possible. Text that could not be coded into one of these categories was coded as "other" and was later re-examined and given a new code. One transcript from each cancer type were read and coded by SS and FW. Coding by SS and FW was then compared with the coding by SK. If any discrepancies in coding arose they were discussed until agreement was reached. Data management and coding were facilitated by NVivo software (V.10).

Table 28 Categorisation Matrix with Definitions

Appraisal interval		
COMMON SENSE MODEL OF ILLNESS	*Threat description*	The time point when a person becomes aware of somatic information. The term 'symptom' is used to denote bodily changes that have been appraised to be something abnormal (rather than fluctuations of normal bodily processes or responses to the environment).
	Heuristics	Rules of thumb that either automatically or with deliberate thought affect decisions relating to the meaning of symptoms and or whether symptoms merit medical care.
	Illness Representations	Illness representations hold facts and beliefs about normal physiological conditions and/or states and disease and can include beliefs about the associated symptoms, the causes, consequences, timeline and perceived controllability of the illness. Illness representations can be abstract (what is expected) and experiential (what is experienced).
	Emotional Response	Individuals have emotional representations and reactions (e.g. fear or anxiety) to the health threat, which might lead to emotion-based coping behaviour.
	Coping Procedures	Specific behavioural responses to health threats (e.g. seeking medical help, self-treatment, monitoring symptoms) rather than general categories of coping (such as problem or emotion-focused coping).
	Re-appraisal	If a coping procedure has failed to improve the symptoms (e.g. due to ineffective self-treatment) this can lead to changes in coping procedures (such as seeking help) or a change in the cognitive or emotional representation.
Reasons to consider/wish to discuss symptoms with HCP *or* Lack of reasons to consider/ wish to discuss symptoms with HCP		
Represents the time point at which an individual believes they have/do not have a motive to consult a HCP about their symptoms and thus consider or do not consider seeking help from a HCP.		
Help-seeking interval		
SOCIAL COGNITIVE THEORY	*Self-efficacy*	A belief about one's ability to successfully perform (health) behaviour.
	Outcome Expectancies	The belief that a given behaviour will or will not lead to a given outcome. Outcome expectations can take three major forms (physical effects, self-evaluative and social reactions). Within each form the anticipated positive outcomes serve as incentives and the negative ones as disincentives.
	Proximal goals	When seeking help is not seen as urgent then competing priorities such as children, co-morbidities, jobs or holidays may lead to an intention not being acted upon or replaced by a different course of action.
	Impediments	Personal impediments may impede performance of the health behaviour itself
	Opportunities	Personal opportunities may encourage performance of the health behaviour itself

Table 29 Categorisation Matrix with Examples

Appraisal Interval		
COMMON SENSE MODEL OF ILLNESS SELF-REGULATION	Threat	- Detection of a bodily change - Description and/or aspects of bodily changes (incl. clinical and physiological factors such as site, size, growth rate, etc.)
	Heuristics for Appraisal	- *Symmetry rule* [experiencing symptoms leads to a search for an illness label and illness labels produce an expectation of symptoms] - *Location rule* [the area of the body in which symptoms arise influences their interpretation] - *Pattern rule* [diffuse, ambiguous symptoms lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Such symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care] -*Rate of Change rule* [symptoms that are worsening, unstable, or increasing in number, and symptoms that have a sudden rather than gradual onset, can indicate illness and provide motivation to seek help promptly] - *Severity rule* [symptoms that are extreme or 'severe' (rather than mild or vague) and disrupt functioning indicate the need for care] - *Novelty rule* [symptoms that are new, different, or incongruent (unexpected) with underlying schema rather than familiar, common, or similar to a co-existing chronic illness can be a key motivator to seek help] - *Duration rule* [symptoms that are persistent or prolonged (compared to previous experience or expectations), rather than short lived or intermittent, can indicate a level of seriousness, which in turn, can be a reason for urgently seeking help] - *Age-Illness rule* [as individuals grow older, they increasingly attribute sensations to the ageing process rather than to illness] - *Stress rule* [ambiguous symptoms are often discounted during times of acute stress and are more likely to be attributed to stress rather than physical illness] - *Optimistic Bias rule* [individuals have a generally optimistic bias in that their interpretations, in keeping with previous experience, and will tend to make innocuous explanations rather than those that are life

COMMON SENSE MODEL OF ILLNESS SELF-REGULATION		threatening] - *Stereotypes rule* [illness schemas (and in turn symptom interpretations) are often governed by stereotypes. For instance, the male 'coronary candidate' is often embedded in illness schemas. Subsequently, when women experience cardiac-like symptoms, cardiac causes tend not to be considered and there is no urgency to seek help] - *Prevalence rule* [symptoms that are perceived to be prevalent in the community are more likely to be considered less threatening (i.e. minor rather than serious). Conversely, symptoms that are seen to be rare are more likely to invoke concern and act as a motivator to seek help] - *Similarity rule* [perceived susceptibility or vulnerability to illness can emerge from perceived similarity in exposure, temperament, physical characteristics between the self and those with a certain illness, and this in turn can influence symptom interpretation]
	Illness Representations	Whether there is a match or mismatch between what is expected and/or experienced. Defined by the following stages: - Identity - Cause - Timeline - Consequence - Control/Cure
	Emotional Response	For example: - Fear - Anxiety - Embarrassment - Worry - Other
	Coping Procedures	For example: - Symptom Monitoring/Watchful Waiting - Self-medication - Ignoring/dismissing symptoms - Adaptations to lifestyle
	Re-appraisal	For example: - Ineffective self-management/self-medication will result in change of coping behaviour - Effective self-management/self-medication

			will not change coping behaviour - Other	
Reasons to consider to / wish to discuss symptoms with HCP			**Lack of reasons to consider to / wish to discuss symptoms with HCP**	
- Cognitive factors (e.g. beliefs about symptoms, something is wrong / serious) - Consequences of symptoms (e.g. interference of symptoms with one's ability to work) - Perceived inability to cope with symptoms (e.g. persistence, symptom salience, failure to self-medicate) - Emotional factors (e.g. anxiety, concern, need for reassurance) - Other			- Cognitive factors (e.g. beliefs about symptoms, nothing is wrong / serious) - No consequences of symptoms (e.g. no interference of symptoms with one's ability to work) - Perceived ability to cope with symptoms (e.g. persistence, symptom salience, aptitude to self-medicate) - Emotional factors (e.g. no anxiety, no concern, no need for reassurance) - Other	
Help-seeking Interval				
SOCIAL COGNITIVE THEORY	Self - efficacy	Personal impediments to accessing care	- Lack of time - General lethargy (e.g. due to depression) - Other	
		Healthcare system impediments	- Accessibility (location of services) - Availability (volume of existing services - Acceptability (patients' attitudes about the HCPs personal and professional character) - Affordability (cost of services or getting to services) - Accommodation (opening hours of service) - Trust in HCP - (Previous) symptoms remaining undetected and/or misdiagnosed as benign by doctors - Professional miscommunication - Waiting list for specialist appointments - Misdiagnosis and/or administrative error - Other	
		Socio-structural opportunities	- Pre-booked appointments - Free healthcare screening - Other	
		Sources of Self-efficacy	- Previous experiences (mastery) - Vicarious experience through social models - Social persuasion - Other	
			Reasons for not seeking help	*Reasons for seeking help*
	Outcome Expectancies	Physical effects	Person believes that seeking help will result in: - Suffering - Unwanted or unpleasant treatment	Person believes that seeking help will result in: - Reassurance - Reduced anxiety /uncertainty

SOCIAL COGNITIVE THEORY			- Being diagnosed with incurable disease - Serious and painful symptoms - Fatal incurable disease - Fear of unpleasant treatment - Loss of sexuality after treatment - Other	- Improved prognosis - Reduced pain or suffering - Other
		Self-evaluative	Person believes that seeking help will have a negative outcome: - Threat to self-identity - Threat to masculinity - Loss of independence - Loss of pride - Other	Person believes that seeking help will have a positive outcome: - Reinforce self-identity - Maintain independence - Other
		Social reactions	Person will not seek help due to: - Embarrassment of sensitive/sexual area - Believe that patient's family/friends think that symptoms are psychosomatic - Disapproval/ rejection/ stigma - Being seen as time waster or neurotic - Being seen as weak - Previous negative experiences of cancer (in family and friends) - Weakness - Seeking help will burden others - Lack of support from family/friends to seek help or advice others not to seek help - False reassurance	Person will seek help due to: - Few inhibitions about wasting doctor's time - Doctors dismissing fears associated with symptoms - Existence of social networks including family and friends - Family/friends directly or indirectly forcing or encouraging contact with HCPs - Other

			- Other	
	Proximal goals		- Help is not sought due to competing priorities (e.g. holiday, work, care of dependents, etc.) - Other	- Symptoms interfere with life or reach crisis point (e.g. symptoms interfering with work, holiday, care of dependents, etc.) - Other

3.4.3 Alterations to Heuristics Definitions

Whilst coding data it became apparent that some of the definitions of heuristics influencing the interpretation of symptoms as outlined by Scott et al. (2013) (see **Table 26**) were similar and could therefore be combined. Others were not clear, did not match original the definition, or needed further clarification. Consequently, some of the definitions for heuristics were modified; the main changes and reasons for these alterations and improvements are outlined below (see **Table 30**).

3.4.3.1 Introduction of a new heuristic: 'Chronology rule'

A new heuristic, the *Chronology rule* was generated. *Chronology rule* is defined as 'the time when symptoms arise guides interpretation: there is a logical link between the occurrence of symptoms and recent events and this underpins the interpretation.'

It became apparent from coding the data that participants sometimes thought that symptoms occurred following a recent event. For example, eating something caused bowel movements, or smoking cigarettes caused someone to cough all night. It is noted that that *Chronology rule* and *Location rule* are two separate entities, as "location" can be defined as the area in the body where symptoms arise, which will subsequently influence interpretation, whereas "chronology" is the time when symptoms arise, which will subsequently guide their interpretation. Therefore, a new definition was generated for *Chronology rule* and *Location rule* as per its usual definition was included.

3.4.3.2 Merging of the Stereotype rule and Similarity rule

Whilst analysing the data it emerged that there were similarities between the two definitions and that data coded under the *Stereotypes rule* could also be coded under the *Similarity rule*, thus the two were not mutually exclusive. *Stereotypes rule* [originally defined as "Illness schemas (and in turn symptom interpretations) are often governed by

stereotypes (Lalljee et al., 1993; Moloczij et al., 2008). For instance, the male 'coronary candidate' is often embedded in illness schemas. Subsequently, when women experience cardiac-like symptoms, cardiac causes tend not to be considered and there is no urgency to seek help (Davison et al., 1991; Dracup et al., 2006; Martin et al., 2004)." (Scott et al., 2013, p55)] was therefore combined with *Similarity rule* [originally defined as "Perceived susceptibility or vulnerability to illness can emerge from perceived similarity in exposure, temperament, physical characteristics between the self and those with a certain illness (Walter et al., 2004), and this in turn can influence symptom interpretation (Higginson, 2008; Molassiotis et al., 2010; Smith et al., 2005)" (Scott et al., 2013, p55)].

Further to this, the *Similarity rule* was altered to become indicative of cancer, because the original definition was not adequate enough to explain why experiencing certain symptoms causes individuals' to interpret the symptoms as indicative of cancer as opposed to (an)other illness(es). It was re-defined as: 'Perceived susceptibility or vulnerability to illness can emerge from perceived similarity in exposure, temperament, physical characteristics between the self and those who had a diagnosis of cancer, and this in turn can influence symptom interpretation'.

3.4.3.3 Clarification to Severity rule and Pattern rule

The definition for the *Severity rule* [originally defined as "Symptoms that are extreme or 'severe' (rather than mild or vague) and disrupt functioning indicate the need for care. (Howell et al., 2008; Leventhal et al., 2005; Mechanic, 1978, 1992; Mora et al., 2002; Safer et al., 1979; Smith et al., 2005)." (Scott et al., 2013, p55)] was modified to only include reference to the impact of symptoms, namely 'Symptoms that disrupt functioning indicate the presence of illness and/or the need for care whereas those that allow normal functioning will reduce motivation to seek help'. This modification was deemed necessary because when coding participants' responses all their symptom descriptions sounded severe and as a result of coding responses under the *Pattern rule* [originally defined as "Diffuse, ambiguous symptoms lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Such symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care (Burgess et al., 2006; Cacioppo et al., 1986; Horne et al., 2000; Macleod et al., 2009; Smith et al., 2005)" (Scott et al., 2013, p55)] there was an overlap between the judgement of symptoms and the pattern of symptoms as referred to in the *Pattern rule*. Consequently, the definition for *Pattern rule* was changed to 'compared to symptoms that are striking or

extreme, symptoms that are diffuse, ambiguous or vague lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Such symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care'. Altering the definition for *Severity rule* and *Pattern rule* made it easier to differentiate between severe and less severe symptoms when coding data with *Pattern rule* referring to the nature of symptoms and *Severity rule* referring to the impact of symptoms.

3.4.3.4 Expansion of the Symmetry rule

The definition for the *Symmetry rule* [originally defined as "There is a bi-directional relationship between symptoms and labels in that experiencing symptoms leads to a search for an illness label and illness labels produce an expectation of symptoms (Diefenbach & Leventhal, 1996)". (Scott et al., 2013, p55)] was modified, because people were labelling, but not necessarily with an illness label, instead having had an explanation or reason for a bodily change. For instance, bodily changes were believed to be something mundane as opposed to an illness. Also given that the *Symmetry rule* occurs before seeking help and so prior to diagnosis it was changed to look at one direction only. Therefore *Symmetry rule* was defined as 'detection of bodily changes stimulates labelling, attributing a cause, explanation or reason for the change'.

Table 30 provides an overview of the modified definitions for the heuristics.

Table 30 Definitions of Heuristics modified during data analysis (Scott et al., 2013)

Heuristic	Definition
Symmetry rule	Detection of bodily changes stimulates labelling, attributing a cause, explanation or reason for the change.
Location rule	The area of the body in which symptoms arise influences their interpretation (e.g., oral pain is 'toothache', and breathlessness is connected to the lungs (rather than the heart).
Pattern rule	Compared to symptoms that are striking, severe or extreme, symptoms that are diffuse, mild, ambiguous or vague lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Such symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care.
Rate of change rule	Symptoms that are worsening, unstable, or increasing in number, and symptoms that have a sudden rather than gradual onset, can indicate illness and provide motivation to seek help promptly. In comparison, symptoms that are getting better/improving, fluctuating, stable, or decreasing in number, can indicate absence of illness and reduce motivation to seek help promptly.
Severity rule	Symptoms that disrupt functioning indicate the presence of illness and/or the need for care whereas those that allow normal functioning will reduce motivation to seek help.
Novelty rule	Symptoms that are new, different, or incongruent (unexpected) with underlying schema rather than familiar, common, or similar to a co-existing chronic illness can be a key motivator to seek help
Duration rule	Symptoms that are persistent or prolonged (compared to previous experience or expectations), rather than short lived or intermittent, can indicate a level of seriousness, which in turn, can be a reason for urgently seeking help.
Age-Illness rule	As individuals grow older, they increasingly attribute sensations to the ageing process rather than to illness.
Stress-illness rule	Ambiguous symptoms are often discounted during times of acute stress and are more likely to be attributed to stress rather than physical illness.
Optimistic bias	Individuals have a generally optimistic bias in that their interpretations, in keeping with previous experience, and will tend to make innocuous explanations rather than those that are life threatening.
Prevalence rule	Symptoms that are perceived to be prevalent in the community are more likely to be considered less threatening (i.e., minor rather than serious). Conversely, symptoms that are seen to be rare are more likely to invoke concern and act as a motivator to seek help.
Similarity rule	Perceived susceptibility or vulnerability to illness can emerge from perceived similarity in exposure, temperament, physical characteristics between the self and those who had a diagnosis of cancer, and this in turn can influence symptom interpretation.
Chronology rule	The time when symptoms arise guides interpretation: there is a logical link between the occurrence of symptoms and recent events and this underpins the interpretation.

3.5 Results

3.5.1 Patient Characteristics

Transcripts from 49 interviews with patients were included in this secondary analysis. Their characteristics are outlined in **Table 31**. 28 participants were female (57%) and had a mean age of 58.64 years, and the 21 male participants (43%) had a mean age of 67.10 years. The overall mean age of participants was 62.34 years (SD = 12.64).

Table 31 Patient Characteristics

Patient ID	Cancer Site	Gender	Age (years)	TTP
Pa1	Pancreas	Female	59	Shortest
Pa2	Pancreas	Male	66	Shortest
Pa3	Pancreas	Female	53	Median
Pa4	Pancreas	Male	79	Median
Pa5	Pancreas	Male	64	Longest
Pa6	Pancreas	Female	57	Longest
Pa7	Pancreas	Female	84	Shortest
Pa8	Pancreas	Male	71	Longest
CRC1	Colorectal	Female	50	Shortest
CRC2	Colorectal	Male	80	Shortest
CRC3	Colorectal	Female	74	Median
CRC4	Colorectal	Female	49	Median
CRC5	Colorectal	Female	67	Longest
CRC6	Colorectal	Female	71	Shortest
CRC7	Colorectal	Female	87	Longest
Or1	Oral	Male	50	Shortest
Or2	Oral	Female	57	Shortest
Or3	Oral	Male	56	Median
Or4	Oral	Female	64	Median
Or5	Oral	Male	64	Median
Or6	Oral	Male	66	Longest
Or7	Oral	Female	50	Longest
Or8	Oral	Male	59	Longest
Or9	Oral	Male	51	Shortest
Res1	Respiratory	Female	68	Shortest
Res2	Respiratory	Female	50	Shortest
Res3	Respiratory	Female	56	Median
Res4	Respiratory	Male	67	Median
Res5	Respiratory	Female	74	Longest
Res6	Respiratory	Female	42	Longest
Res7	Respiratory	Female	54	Shortest
Res8	Respiratory	Male	63	Longest
Mel1	Melanoma	Male	82	Shortest
Mel2	Melanoma	Female	54	Shortest
Mel3	Melanoma	Male	84	Median
Mel4	Melanoma	Female	36	Median
Mel5	Melanoma	Male	72	Longest
Mel6	Melanoma	Female	40	Longest
Mel7	Melanoma	Male	48	Shortest
Mel8	Melanoma	Female	63	Longest
Br1	Breast	Female	49	Shortest
Br2	Breast	Female	71	Shortest
Br3	Breast	Female	53	Median
Br4	Breast	Female	55	Median
Br5	Breast	Female	55	Longest
Pr1	Prostate	Male	79	Shortest

Patient ID	Cancer Site	Gender	Age (years)	TTP
Pr2	Prostate	Male	70	Median
Pr3	Prostate	Male	65	Median
Pr4	Prostate	Male	58	Longest
Pr5	Prostate	Male	82	Longest

3.5.2 Qualitative Themes

The contributing factors within the help-seeking interval were coded as part of this study to ensure all aspects relevant to the TTP were considered. However, only the findings of the contributing factors within the appraisal interval were further analysed and reported here.

The data are reported in the following sections:

3.5.2.1 Appraisal Interval

3.5.2.1.1 Heuristics for appraisal

3.5.2.1.2 Illness representations about cancer

3.5.2.1.3 Coping procedures

3.5.2.1.4 Emotional responses

3.5.2.1.5 Re-appraisal

3.5.2.2 Reasons and lack of reasons to consider discussing symptoms with a HCP

Extracts from interviews illustrate the results; each quotation is contextualised by the participant's patient ID, suspected/actual cancer site, gender, age and TTP.

3.5.2.1 Appraisal Interval

3.5.2.1.1 Heuristics for Appraisal

Figure 5 demonstrates the number of participants coded as supporting or contradicting a heuristic. **Figure 6** demonstrates the number of participants coded as referring to a heuristic.

244 separate quotes from the 49 transcripts were considered to support the use of cognitive heuristics. 43 participants each demonstrated the use of at least one heuristic and on average, participants used 3 different heuristics. The heuristics to which people referred to the most were: the *Rate of Change rule* (n = 59 supportive quotes from n = 29 (59%) participants), *Symmetry rule* (n = 37 supportive quotes from n = 18 (37%) participants), *Duration rule* (n = 30 supportive quotes from n = 18 (37%) participants), *Pattern rule* (n = 23 supportive quotes from n = 11 (22%) participants) and *Chronology rule* (n = 22 supportive

quotes from n = 12 (24%) participants). There was also some evidence for the *Severity rule* (n = 15 supportive quotes from n = 10 (20%) participants), *Novelty rule* (n = 14 supportive quotes from n = 9 (18%) participants), *Age-Illness rule* (n = 13 supportive quotes, from n = 10 (20%) participants), *Similarity rule* (n = 11 supportive quotes from n = 9 (18%) participants), *Location rule* (n = 11 supportive quotes from n = 7 (14%) participants), and *Optimistic Bias rule* (n = 9 supportive quotes from n = 6 (12%) participants). There was no evidence of any participants referring to either the *Stress-Illness rule* or *Prevalence rule.* Quotes that were contradictory or unsupportive of the heuristics were, in contrast, relatively rare, with only 11 contradictory quotes across the 49 participants.

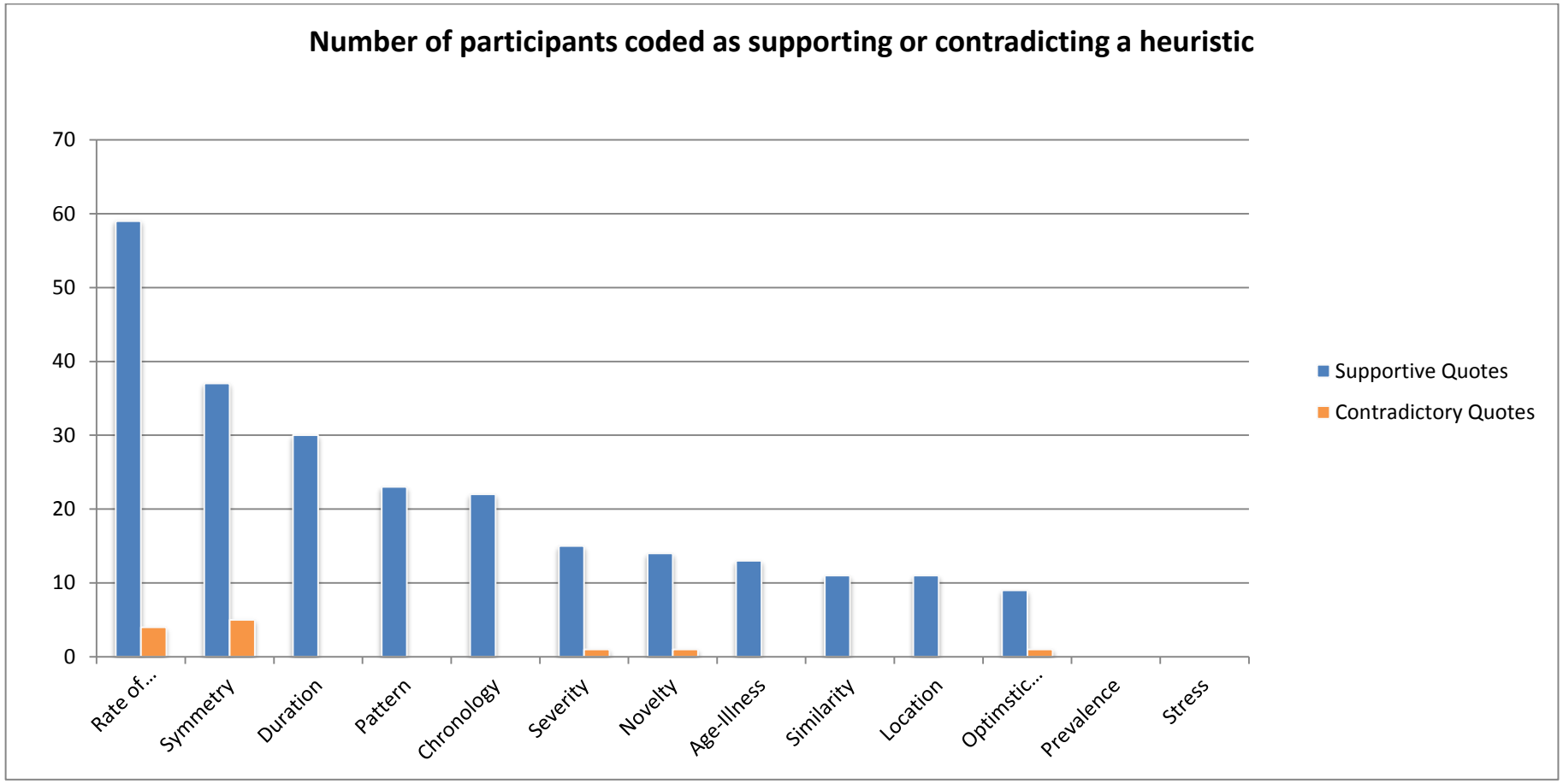

Figure 5 Number of participants coded as supporting or contradicting a heuristic

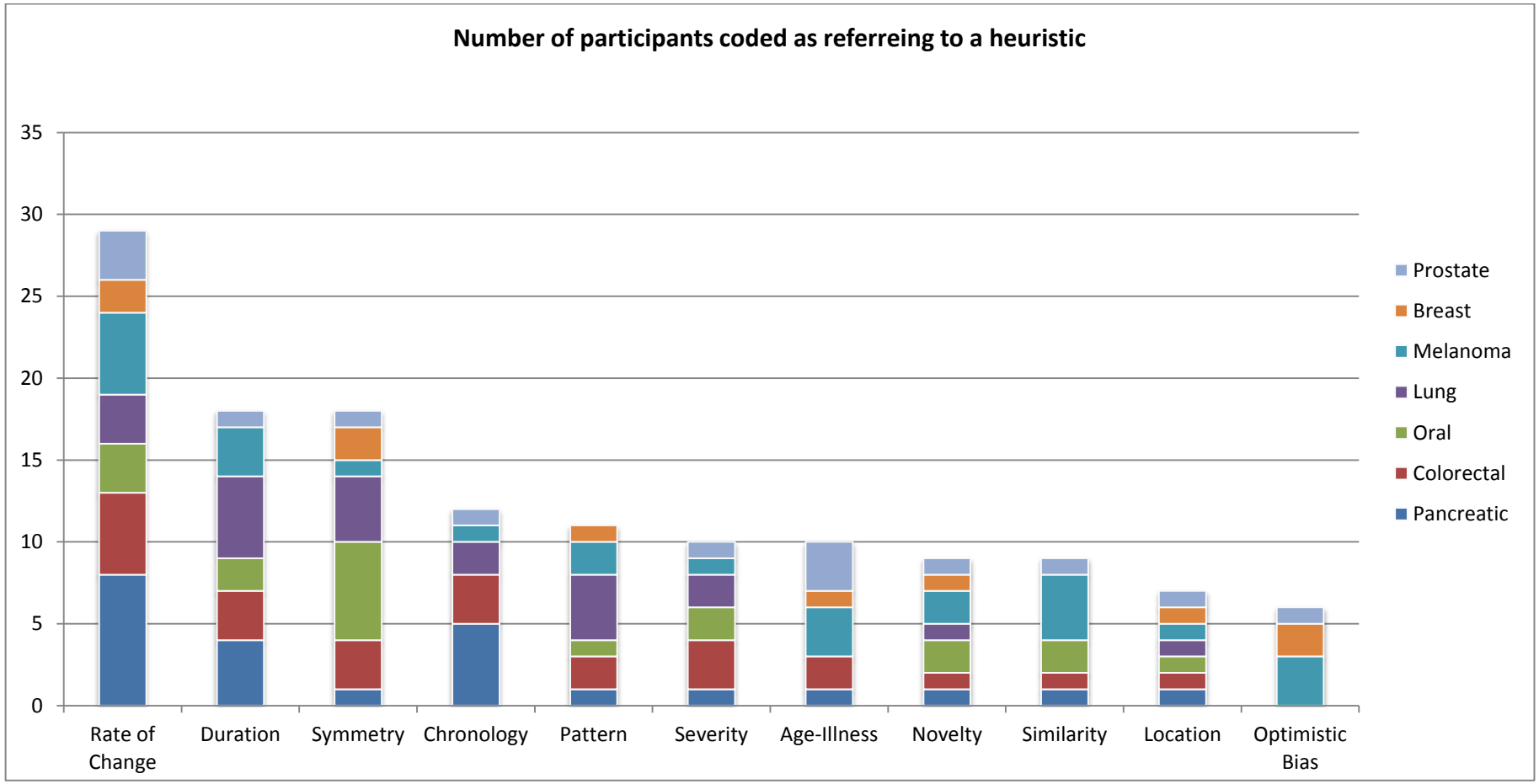

Figure 6 Number of participants coded as referring to a heuristic

For the purpose of this analysis, examples of supportive quotes (responses that support the heuristics definition) and contradictory quotes (responses that contradict the heuristics definition) are further explained below to demonstrate how participants used heuristics within the appraisal interval to evaluate symptoms and decide whether symptoms required medical care.

3.5.2.1.1.1 Rate of Change rule

The participants who most commonly referred to the *Rate of Change rule* were individuals with oral, colorectal and pancreatic symptoms, with five participants in each group referring to the heuristic. Participants with melanoma, respiratory, prostate and breast symptoms also referred to use of the rule.

For the majority of individuals, a change in the nature of their symptoms, such as experiencing additional changes or symptoms worsening, altered their symptom perception and ultimately provided the motivation to seek help.

> *"Nothing really until it got another lump come on it to be honest, that mole like it was that and then it got like a spot come on it so only like in the corner of it and I was like oh that's really new so I should go and get that looked at."* [Mel4, Melanoma, Female, 36 years, Median TTP]

> *"It certainly wasn't getting any better, it was getting worse if anything and so I thought it was worthwhile getting it checked out."* [Pa4, Pancreas, Male, 79 years, Median TTP]

Nevertheless, there was one case were symptom interpretation did not match the *Rate of Change rule*. One participant noted that symptoms were worsening; however, help was not sought as she had hoped that the symptoms would pass.

> ***"****I thought oh God this isn't so good, but I thought well you know it still might sort itself out"* [Or7, Oral, Female, 50 years, Longest TTP]

3.5.2.1.1.2 Symmetry rule

There was overall support for the *Symmetry rule* (most commonly referred to by individuals with oral symptoms and respiratory symptoms). A specific explanation or label for a bodily change (not necessarily illness) was sought by participants once it had been noticed.

> *"Since I'd been outside to a barbeque and I thought, oh well I've been bitten, it's just bitten there on the mole, you know because there was lots of, ah, I'd had like a bite on my leg as well but when it didn't go down within sort of a couple of days."* [Mel2, Melanoma, Female, 54 years, Shortest TTP]

> **"***No I always thought it was something to do with [the] filling. The whole time. The whole time it never occurred to me that it could be something other than something to do with the tooth. Even though it may have changed in what's going on their it's always felt to me as the root cause"* [Or7, Oral, Female, 50 years, Longest TTP]

However, there were five instances (from participants with melanoma, breast, prostate and colorectal symptoms) where statements seemed to dispute the *Symmetry Rule*. For example, participants described how despite noticing bodily changes they did not contemplate any further about their symptoms. Consequently, symptoms were often dismissed.

> *"… couple of times in the shower, you know earlier I noticed that it you know it got lumpy but you know as I said I wasn't really paying attention to it."* [Br5, Breast, Female, 55 years, Longest TTP]

> *"It wasn't in my mind on a regular basis. I would notice it occasionally when I was having a bath and would think, "Oh, it looks as if it might be changing," but that's as far as my mind would go."* [Mel5, Melanoma, Male, 72 years, Longest TTP]

For other participants, they were unable to explain or label the symptom(s).

"but when it came back again I thought no it can't be because it wouldn't keep coming back like this, it would just be a virus which I had or a bacteria and then that would go, so then I thought no, it's not gastroenteritis" [CRC1, Colorectal, Female, 50 years, Shortest TTP]

3.5.2.1.1.3 Duration rule

Duration of symptoms was a critical motivator towards initiating help-seeking for all cancer types, except for those with breast symptoms who did not refer to using the *Duration rule* at all. The *Duration rule* was most commonly referred to by people with respiratory and pancreatic symptoms.

Many individuals initially took on a watchful waiting approach and decided to monitor their symptoms for a prolonged period. On-going bodily changes eventually led individuals to interpret their symptoms as something serious and that help should be sought.

"after a few days it didn't go down or anything so I thought oh I'd better go and get it checked out at my doctor's surgery." [Mel2, Melanoma, Female, 54 years, Shortest TTP]

"That caused me concern because it was going on and on." [Pa4, Pancreas, Male, 79 years, Median TTP]

Nevertheless, contrary to the rule, even though one participant was aware of the mole for a long time no help was thought as symptoms did not get more severe over a prolonged period.

"Well, I'm very freckly, as it is, but I did notice that I, probably a couple of years ago, I had what was a large freckle sort of developed, and ended up, I suppose, the size of a thumbnail. Two-tone in colour and quite a distinct, like a sort of maple leaf, the darker colour was a maple leaf. But it was flat, it was just there and it, from my point of view it didn't really change at all over the couple of years, and I kept an eye on it." [Mel8, Melanoma, Female, 63 years, Longest TTP]

3.5.2.1.1.4 Pattern Rule

There was supportive evidence for the *Pattern rule* for all cancer types except those with prostate symptoms. This rule appeared to be particularly evident in those with respiratory symptoms where striking, severe aspects of symptoms triggered perceptions of seriousness and the need for medical help.

> *"because every time when I coughed it felt like as if I was ripping my lungs apart, it was really painful".* [Res2, Respiratory, Female, 50 years, Shortest TTP]

> *"…remember being over the pan and it came up so I saw the gravy and bits and all sorts. And then what frightened me, black, it was bloody black. It was as though it was from the bowels of the earth, I've never seen that before. And I don't know whether it was dead blood or what the hell it was but...Ooh, the smell was."* [Pa8, Pancreas, Male, 71 years, Longest TTP]

> *"But you know that ... that really excruciating pain, it was really quite painful when she stood there"***[Interviewee became aware of symptoms after her cat stood on her]**. *"It sort of woke me up a bit, sort of thinking, oh there is something wrong."* [Br5, Breast, Female, 55 years, Longest TTP]

3.5.2.1.1.5 Chronology rule

Individuals with pancreatic, colorectal, respiratory, melanoma and prostate symptoms referred to the *Chronology rule*, whereby explanations given for the cause of symptoms were contextualised as a reaction to specific events. For example, individuals made a link between the occurrences of symptoms and the type of food they ate.

> ***"****so I thought well it's Diverticulosis if I was a bit bloated or you know, if I had a mild tummy pain I thought 'oh dear, I shouldn't have had whatever I had to eat last night' or whatever, you know, or 'I ate it too quickly' or 'I was jumping up and down at the table serving other people' or something"* [CRC5, Colorectal, Female, 67 years, Longest TTP]

> *"My husband and I ate exactly the same meal and he was a bit burpy as well so I decided it was possibly cauliflower"* [Pa1, Pancreas, Female, 59 years, Shortest TTP]

There was no evidence for the *Chronology rule* in participants with oral or breast symptoms.

3.5.2.1.1.6 Severity rule

The severity rule was evidenced across all cancer types, apart from participants with breast symptoms. Some participants noted that they came to think their symptoms might be indicative of something serious once symptoms affected mobility. For example, being unable to stand, an inability to get out of bed or having to lay down. In turn, the urgency to seek help immediately was acknowledged.

> *"Anyway, the final thing came when erm Monday night I went to bed and it started bleeding and it just went on, and on and on it was pouring out. So my partner rang the ambulance"* [Or6, Oral, Male, 66 years, Longest TTP]

> *"but I'd called the paramedics that morning, because by this time I, my mobility, my back, I was in such agony with my back, I could hardly stand, I couldn't get to the toilet on me own, I couldn't get out of bed on my own, and really the symptoms of flu was, seemed far less than the pain in my back, so, the pain in my back was taking over the flu symptoms."* [Res7, Respiratory, Female, 54 years, Shortest TTP]

Again, in support of the *Severity rule*, individuals were often not concerned about their symptoms if they experienced bodily changes that allowed normal functioning to continue. If this was the case, help-seeking was not seen as a necessary course of action.

> *"and just because of one spot on my leg of course I don't need a doctor because I still I am going to sport centre, I am working, I am doing at home everything so I can do it, and yeah, I feel fine, but that's fine, it's just normal, and I didn't feel any other like symptoms, it's just I was very tired."* [Mel6, Melanoma, Female, 40 years, Longest TTP]

On the other hand, contrary to the *Severity rule*, one participant's symptom disrupted her normal functioning; however, help was not sought because she found means to adapting to her symptoms.

> ***"****sometimes I couldn't go into lectures until it had gone off. I used to have to lay down on the seat, they knew about it my tutors and my friend would just go in and they'd just say 'Mary? Oh I see, she'll be here in a bit'"* [Pa6, Pancreas, Female, 57, Longest TTP]

3.5.2.1.1.7 Novelty rule

There was some evidence for the *Novelty rule* from all groups. Individuals often became concerned when they experienced symptoms that were new, different to symptoms experienced in the past, or if symptoms were unexpected.

> ***"****And that to me was odd because I'd never seen anything like that before, and that's what suddenly made me curious and wonder what it was."* [Mel5, Melanoma , Male, 72 years, Longest TTP]

> ***"****I had definitely felt um, a lump underneath my armpit. So I'm thinking, I'm really in trouble now because I never had a lump in my armpit before, even with the other breast being removed there was no lymph glands affected. …I just knew straight away, I thought this is it now, because I'd never felt a lump underneath my arm with the other one. So I thought this is - I'm in deep shit now."* [Br4, Breast, Female, 56 years, Median TTP]

Previous experiences of a condition could dissuade a participant of the potential seriousness of new bodily changes. For instance, a female who presented with melanoma symptoms failed to seek help immediately, because the symptoms were dismissed as they were not distinct from existing symptoms.

> *"I have a lot of like these spots on my skin so I never paid attention*" [Mel6, Melanoma, Female, 40 years, Longest TTP]

However, one participant described how her symptoms were not completely new as she had experienced similar symptoms in another location before. This experience helped her

to make a link between her previous and new symptoms which in turn promoted help-seeking, rather than diminishing the need to seek help.

> *"I'd had ear problems with my ear on the other side and I just thought I really can't afford to have anything with this ear happen as well. So that was another push for me to get something done about it."* [Or7, Oral, Female, 50 years, Longest TTP]

3.5.2.1.1.8 Age-Illness rule

The *Age-Illness rule* was mainly referred to by those with prostate, melanoma, and colorectal symptoms and less so among those with breast and pancreatic symptoms. Especially in the elderly, the cause of symptoms was attributed to old age rather than a specific illness.

> *"You're bound to get something when you get older, you think to yourself 'ah, well, it's just nothing'"* [Mel1, Melanoma, Male, 82 years, Shortest TTP]

> *"you know, you get to my age, you get all sorts of symptoms, but you know, it's age, things don't work as well"* [CRC5, Colorectal, Female, 67 years, Longest TTP]

There was no evidence of use of this heuristic among those with oral or respiratory symptoms.

3.5.2.1.1.9 Similarity rule

The *Similarity rule* was most commonly cited amongst individuals with melanoma, but there was also evidence in those with oral, colorectal, prostate and pancreatic symptoms. Individuals with respiratory and breast symptoms did not refer to this heuristic.

When individuals thought that they had a personal predisposition to cancer, for example because of family history or because friends had been diagnosed with cancer, this often guided their symptom interpretation.

> *"And I went to see my doctor, I was a bit worried then because my boy at 40 he had a melanoma on his arm and at 50... they apparently never got all the melanoma out and it came back*

again and it came back with a vengeance and he died within three months. […] And ah, you know, more or less the reason that I went was because of my boy" [Mel3, Melanoma, Male, 84 years, Median TTP]

"Well I thought something could be wrong 'cause I hadn't ... I had friends, I ... I know ... I've got five friends, two of them died from the cancer. Ah, and there is three others that I know that have been treated." [Pr5, Prostate, Male, 82 years, Longest TTP]

3.5.2.1.1.10 Location rule

Although the *Location rule* was not frequently cited, the location of bodily changes guided symptom interpretation and subsequent initiation of help-seeking behaviour for one participant with each cancer type.

"it felt as though… it seemed to me as though the tooth…something around the tooth was rubbing against the underside of my tongue because it started to get red mark appearance, like slight, almost like it was taking off the surface of the skin [...]." [Or7, Oral, Female, 50 years, Longest TTP]

3.5.2.1.1.11 Optimistic Bias rule

Evidence in support of the *Optimistic Bias rule* only came from participants with breast, melanoma and prostate symptoms. Bodily changes were often recognised by these participants; nevertheless, help was not sought. This perception may be due to the fact that they did not consider themselves to be susceptible to an illness. This was especially true if participants rarely experienced an illness in the past or had recently received a negative test result.

"I don't know, well in my life I don't know, I can count these times when I went to the doctor […] like I was thinking I am very strong and I am healthy and so I don't need the doctor" [Mel6, Melanoma, Female, 40 years, Longest TTP]

"When I first myself um, discovered it. But um, I actually had ... I was thinking to myself, maybe it's nothing there because in

September of that year I'd had a mammogram done." [Br4, Breast, Female, 56 years, Median TTP]

However, statements that did not support the *Optimistic Bias rule* were also given by participants with breast (n = 1) and melanoma (n = 2) symptoms. For example, one participant highlighted that, because he never experienced an illness in the past, he thought that the change on his skin might be an indicator that something is wrong, as if he was due to get some form of illness.

> ***"****I just thought oh, I've never ever had anything wrong, I've not [had my] appendix out or anything and I just thought oh maybe this is my thing, um, you know, skin maybe is going to be my problem area."* [Mel2, Melanoma, Female, 54 years, Shortest TTP]

3.5.2.1.2 Illness representations about cancer

Figure 7 demonstrates the number of participants coded as having a *match* or *mismatch* in illness representations about cancer. **Figure 8** demonstrates the number of quotes coded as a match or mismatch in illness representations about cancer.

Overall, there was little evidence for illness representations about cancer, with a *match* coded for four participants (number of quotes coded for a *match* = 8). Few individuals noted that they realised that their symptoms might be suggestive of something serious such as cancer.

> *"I had nothing else, I couldn't think of anything else that grew on your skin like that. I had no kind of ailments, you know, where skin goes peculiar, and it struck me as odd. That's why I went because I thought that's all it could be, and if it wasn't that, it was nothing."* [Mel5, Melanoma, Male, 72 years, Longest TTP]
>
> **"When you found a lump, did you try anything? Did you ... have you had sort of alternative medicines?"**
> *"No, I um ... no, no I didn't try anything."*
> **"No. Yeah."**
> *"No I didn't do anything at all. I probably knew in my own consciousness that it would have to be removed and that it was cancer."* [Br4, Breast, Female, 56 years, Median TTP]

Seven participants were coded as having a *mismatch* between their experience of symptoms and their expectations of cancer (number of quotes coded for *mismatch* = 9). A *mismatch* was most commonly cited amongst participants with colorectal symptoms (n = 3), melanoma (n = 2) and breast symptoms (n = 2), followed by one participant each with oral and respiratory symptoms. There was no evidence of a *mismatch* amongst individuals with pancreatic and prostate symptoms.

Participants gave a range of explanations for a *mismatch*. For example, some participants observed that their bodily changes did not match their representations of cancer symptoms.

> *"I mean I would have thought if it had... a melanoma would have come up, it would have come up like a sore, you know, that's how I thought it would come up, you know after, with my son's."* [Mel3, Melanoma, Male, 84 years, Median TTP]

Individuals also stated that they did not think they would get cancer as they led a healthy lifestyle and did not engage in any risky health behaviours (e.g. smoking or drinking) and thus did not consider cancer as a possible cause of their symptoms.

> *"I mean the thing is I didn't ever feel I was a candidate for bowel cancer because there's no family history, I'm one of these people that, you know, have my five fruit and veg a day and take exercise and I don't smoke and I've never drunk alcohol other than the odd glass of wine, I just don't like spirits, it's not virtue, I just don't like it, and you know, I thought all the things that, you know, are supposed to be risk factors I didn't have, so although I probably had the symptoms a long time I just thought, you know, you get to my age, you get all sorts of symptoms, but you know, it's age, things don't work as well …"* [CRC5, Colorectal, Female, 67 years, Longest TTP]

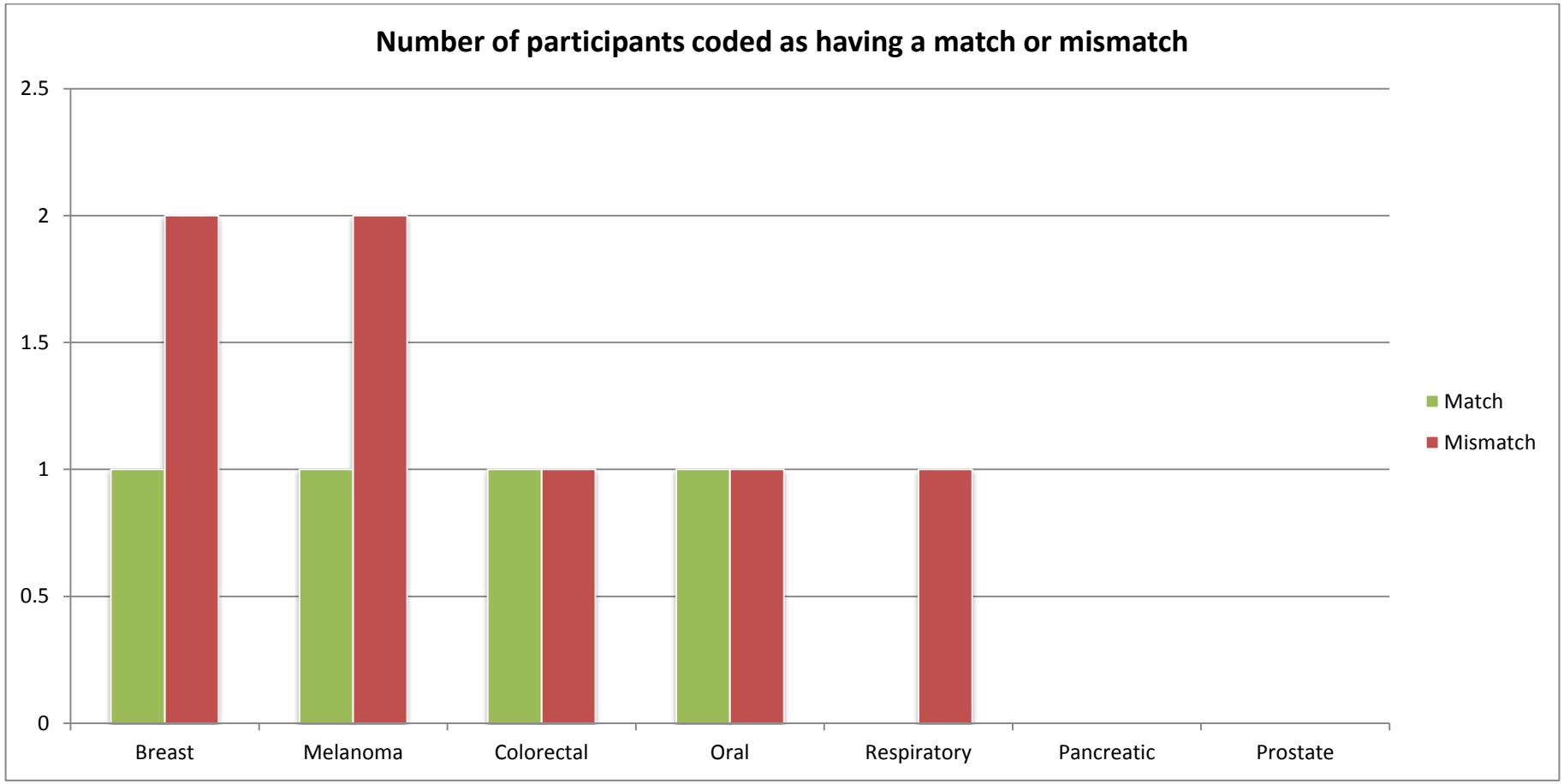

Figure 7 Number of participants coded as having a match or mismatch in illness representations about cancer

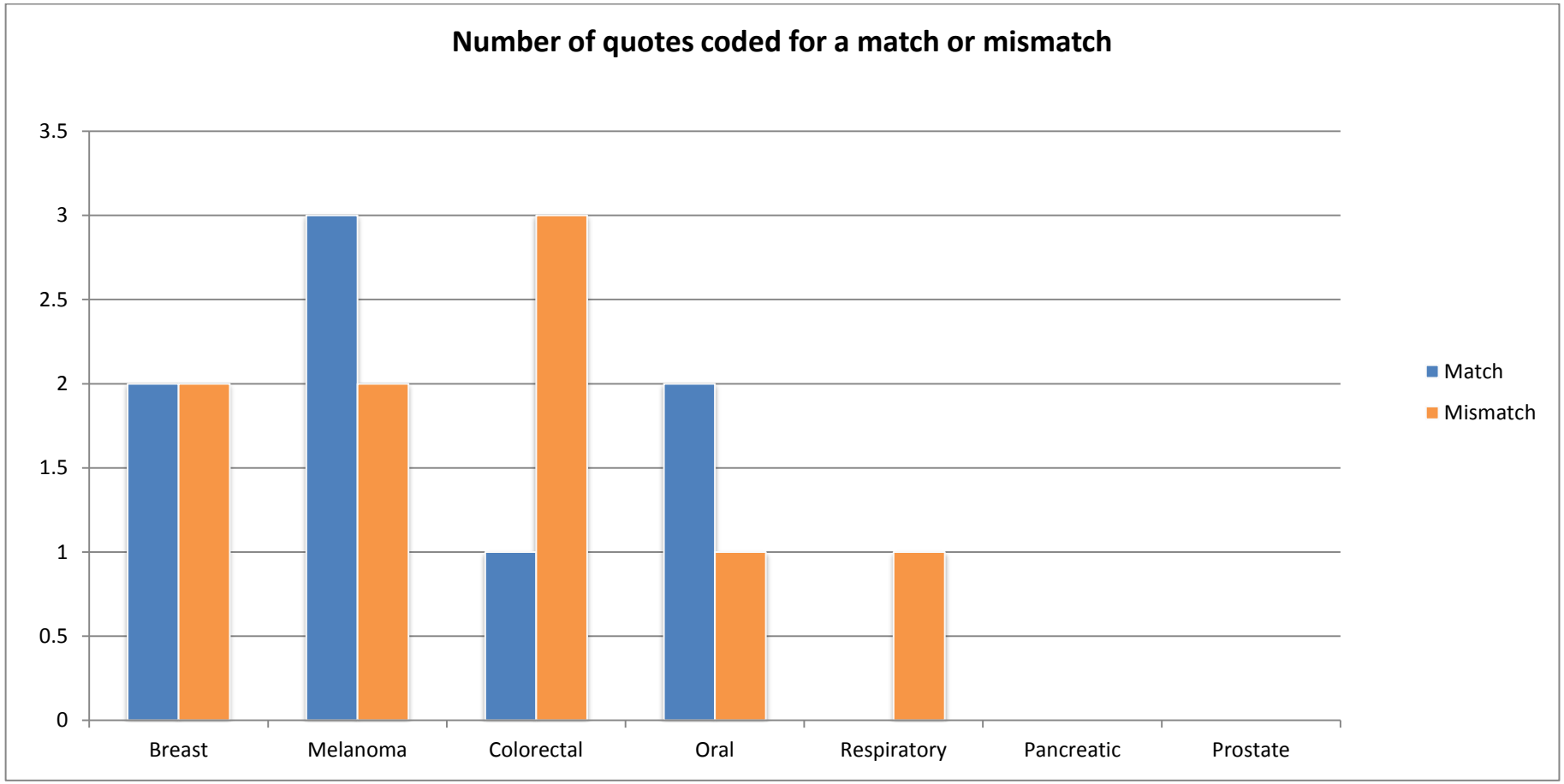

Figure 8 Number of quotes coded as a match or mismatch in illness representations about cancer

3.5.2.1.3 Coping Procedures[24]

Figure 9 demonstrates the number of participants coded as using coping procedures. **Figure 10** demonstrates the number of quotes coded for coping procedures.

The most prevalent coping procedures within the appraisal interval were *self-medication* (n = 49 quotes from 25 (51%) participants), followed by *symptom monitoring and watchful waiting* (n = 21 quotes from 13 (27%) participants), *ignoring and/or dismissing symptoms* (n = 21 quotes from 11 (22%) participants) and *adaptations to lifestyle* (n = 15 quotes from 8 (16%) participants).

[24] As outlined in **Table 28** coping procedures are defined as particular behavioural reactions to health threats (e.g., seeking medical help, self-treatment, monitoring symptoms) instead of general coping mechanisms (e.g. problem- or emotion-focused coping) (Scott et al., 2013).

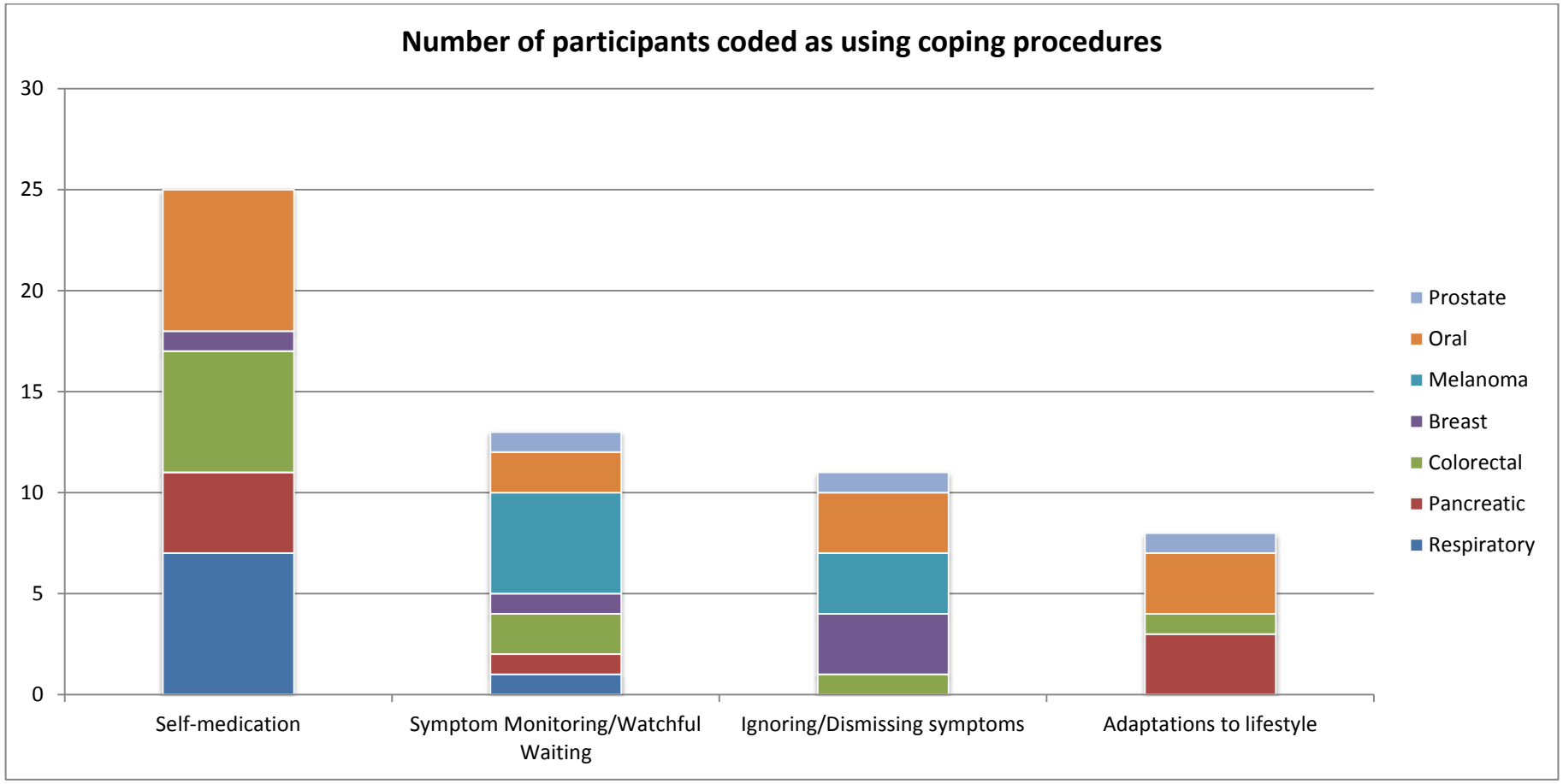

Figure 9 Number of participants coded as using coping procedures

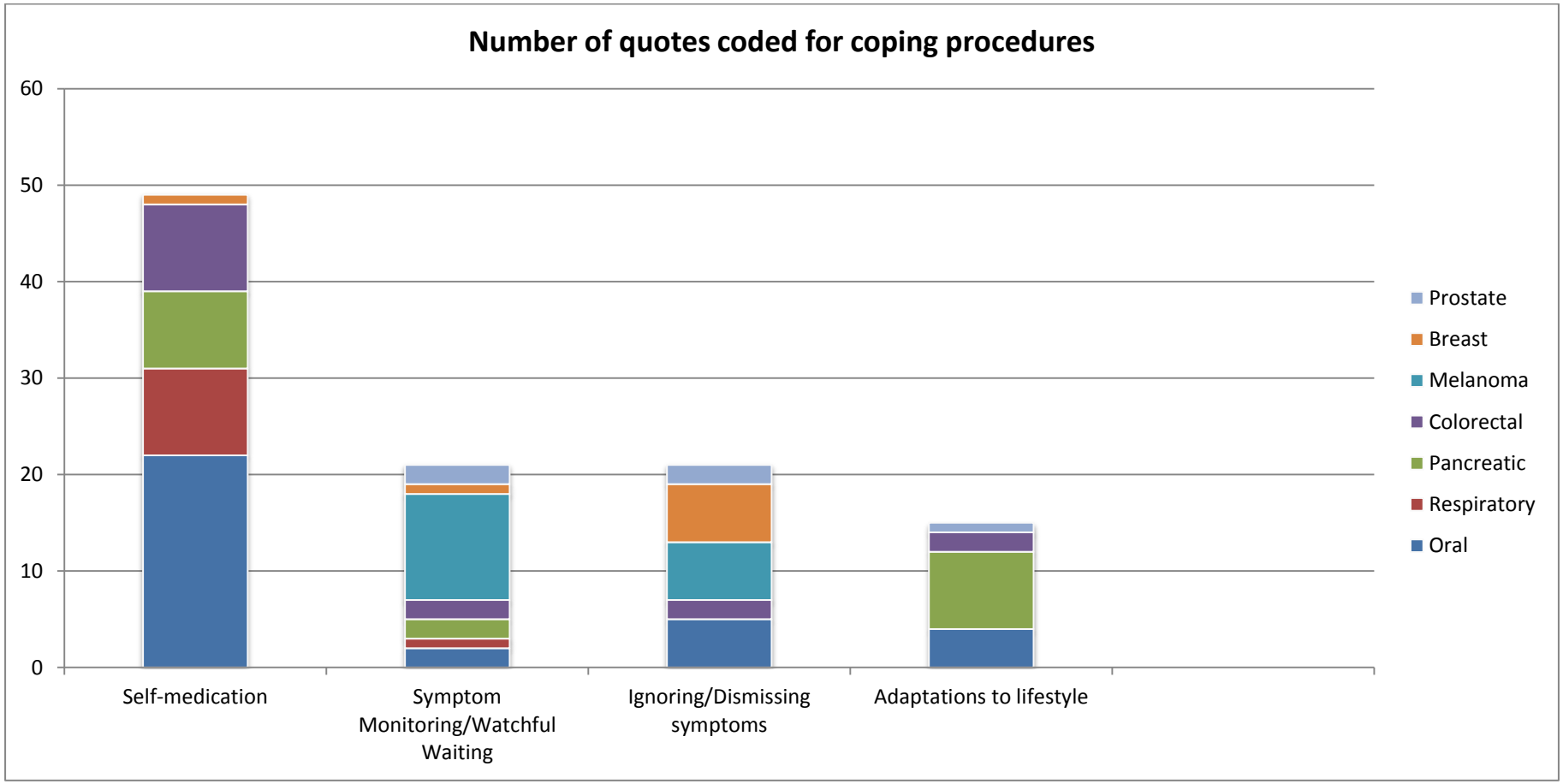

Figure 10 Number of quotes coded for coping procedures

The data regarding numerous coping procedures are further explained below.

3.5.2.1.3.1 Self-medication

The type of medication used to cope with symptoms varied between potential cancer types and was usually dependent on individual's interpretation of the problem and where the symptom(s) arose. For example, people with oral (n = 7) symptoms tended to gargle with salt water, use mouthwash or antibiotics when prescribed, as well as other medications such as Beconase or Paracetamol. People with pancreatic (n = 4) or colorectal (n = 6) symptoms predominantly used medications for indigestion or tummy ache that were either purchased over the counter (OTC) or prescribed by their doctor. On the other hand, individuals with respiratory (n = 7) symptoms used OTC cough medicine, allergy tablets or Paracetamol to ease the pain, as well as antibiotics prescribed by their doctor. There was little or no evidence of self-medication as a coping procedure among individuals with breast (n = 1), prostate (n = 0) and melanoma (n = 0) symptoms.

Some people noted that they did not take any medications for their symptoms. The majority did not state why they did not self-medicate, apart from one person with colorectal symptoms who mentioned that she only takes medication when severely ill and believed that *"if you've got a symptom you need to know why you're treating it before you start to treat it"* [CRC5, Colorectal, Female, 67 years, Longest TTP]

3.5.2.1.3.2 Symptom Monitoring and Watchful Waiting

There was evidence of *Symptom monitoring and/or watchful waiting* across all groups, nevertheless it was most prevalent amongst individuals with melanoma (n = 5) with many participants remarking that they frequently monitored their symptoms before they decided to visit a HCP. The duration of symptom monitoring ranged from a few days to years. Participants talked of how they were monitoring their symptoms to see whether there would be a change or waiting for improvement.

> "*So, I just, on a regular basis, kept watching it, and very, very slowly it started to expand*." [Mel5, Melanoma, Male, 72 years, Longest TTP]

3.5.2.1.3.3 Ignoring and/or dismissing symptoms

Participants with breast (n = 3), melanoma (n = 3) and oral (n = 3) symptoms mentioned that they ignored and/or dismissed their symptoms as a coping procedure. There was no evidence of ignoring and/or dismissing symptoms amongst people with respiratory and pancreatic symptoms.

Symptoms were frequently ignored and/or dismissed because individuals thought that their bodily changes were harmless in nature and would be short lived.

> *"[…] I didn't really think about it beyond that, I just always hoped things would go away and then I won't have to think about them anymore."* [CRC1, Colorectal, Female, 50 years, Shortest TTP]

Other reasons why people dismissed symptoms included failure to take notice of bodily changes, mental health problems or similar bodily characteristics such as freckles that could make it difficult to notice bodily changes.

> *"You know I really wasn't paying much attention to it, because I was probably more into the ... into the depressed mode than anything else."* [Br5, Breast, Female, 55 years, Longest TTP]

> *"But I didn't pay any attention because of my type of skin and colour of my hair, I have a lot of like these spots on my skin so I never paid attention"* [Mel6, Melanoma, Female, 40 years, Longest TTP]

3.5.2.1.3.4 Adaptations to lifestyle

During the appraisal interval some individuals commented that their symptoms started to interfere with their day to day lives or functioning. Adaptations to lifestyle were for the most part made amongst individuals with oral (n = 3) and pancreatic (n = 3) symptoms, but adaptations to lifestyle were infrequently made by individuals across other cancer groups. One participant each amongst individuals with colorectal and prostate symptoms was coded as making adaptations to their lifestyle as a coping procedure, whereas no evidence was found for individuals with melanoma, respiratory and breast symptoms. If adaptations to lifestyle were made they mostly consisted of changes in individuals' eating behaviour.

For example, individuals noted that they started to eat smaller portions or decided to eliminate certain foods.

> *"Eliminated [laughs] virtually all my fruit so I was just very careful, stopped drinking alcohol thinking that... Because I could feel it was uncomfortable in my throat."* [Pa1, Pancreas, Female, 59 years, Shortest TTP]

> *"I think it was a very gradual process with the changing in eating habits. Because you know it wasn't something where I said oh I can't eat this anymore. It was more like I was managing to… you know I was doing the best I could until I got to the point where I couldn't do it anymore and then I'd have to lower down the type of foods I could eat. It was a very subtle thing of changing"* [Or7, Oral, Female, 50 years, Longest TTP]

> *And I've armed myself with, you know, with these special disposable pads and some things like that, so if the worse come to the worse and I'm somewhere and it, you know, it just happens, then, you know, I don't embarrass myself or anybody else around, and then in the quietness of me being in the loo on my own I can sort myself out."* [CRC2, Colorectal, Male, 80 years, Shortest TTP]

3.5.2.1.4 Emotional Responses

Figure 11 demonstrates the number of participants coded as (not) having an emotional response to symptoms. **Figure 12** demonstrates the number of quotes coded for no/an emotional response to symptoms.

Overall there was little mention of emotion within the transcripts, whether that be an emotional response (n = 15 quotes from 11 (22%) participants) or lack of an emotional response (n = 15 quotes from 14 (29%) participants). An emotional response was most prevalent for people with pancreatic (n = 4, number of quotes = 6) symptoms. People with respiratory symptoms most commonly mentioned that they experienced no emotional response (n = 5, number of quotes = 5).

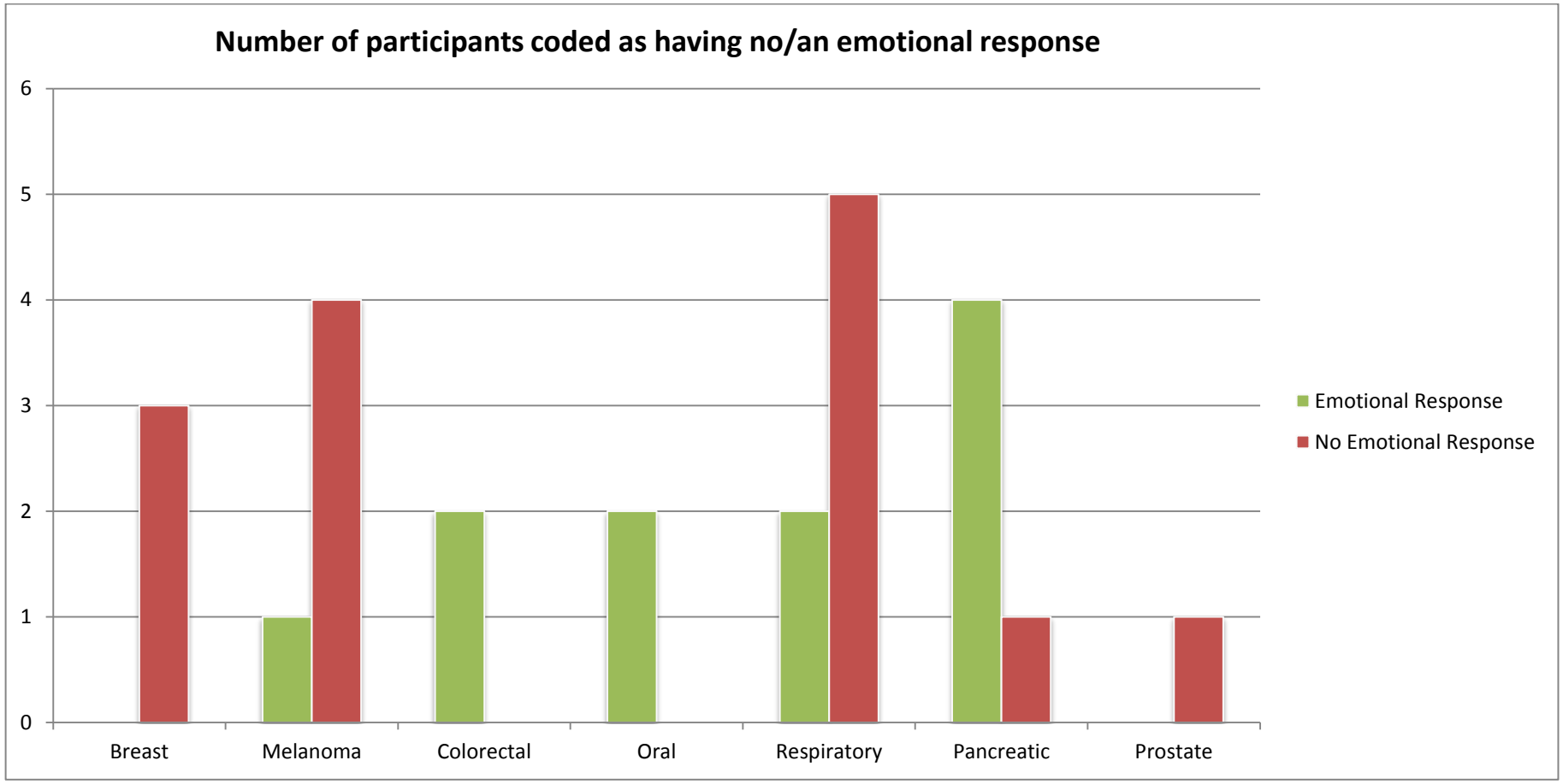

Figure 11 Number of participants coded as having no/an emotional response to symptoms

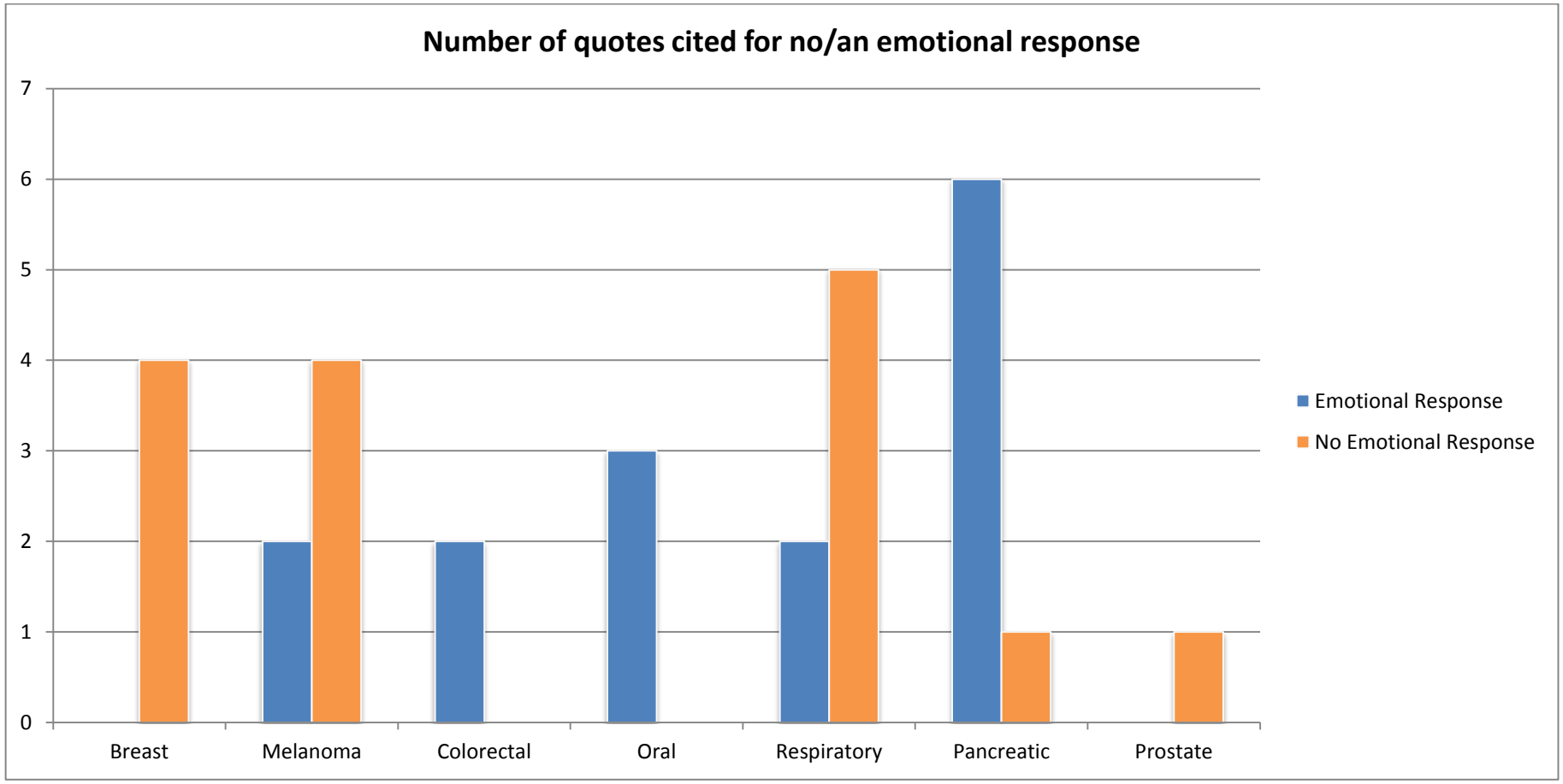

Figure 12 Number of quotes coded for no/an emotional response to symptoms

When patients reported worry, anxiety or fear this was usually a consequence of the striking nature of symptoms.

> *"Because I'd never had heartburn in me life and I mean, it worried me initially when I'm getting pains here and I'm thinking..."* [Pa5, Pancreas, Male, 64 years, Longest TTP]

> *"And then what frightened me, black, it was bloody black. It was as though it was from the bowels of the earth; I've never seen that before. "*[Pa5, Pancreas, Male, 64 years, Longest TTP]

> *"Especially when it bled, yeah I was sort of, I was quite frightened and that I think probably that was the turning point from thinking 'oh it's nothing, you know, it won't happen to me' and thinking 'this potentially could be something quite serious'. "*[Mel4, Melanoma, Female, 36 years, Median TTP]

Nevertheless, individuals also indicated that they were often not anxious, worried or concerned about their bodily changes. Sometimes this was due to the way they generally encountered problems, or due to the inconsequential nature of symptoms.

> *"it's the practical choice, you know, go to the doctor, that's the practical decision to do, you know, what, I'm not going to worry while I'm on holiday, I'm not going to worry about it until I get a diagnosis and dependent on the diagnosis then what can I do. There's two things in my, in my armoury, or in my, in my philosophy. Can you do anything about it? Yes, then do something about it. Can you do anything about it? No I can't, so don't worry about it."* [Mel4, Melanoma, Female, 36 years Median TTP]

> ***"And did the symptoms rapidly get worse over that period do you think?"***
>
> *"They were getting worse. They were getting worse but again I wasn't concerned because I just thought it was muscular and muscular's fine, you know"* [Res4, Respiratory, Male, 67 years, Median TTP]

3.5.2.1.5 Re-appraisal

Figure 13 demonstrates the number of participants coded for using symptom re-appraisal. **Figure 14** demonstrates the number of quotes coded for re-appraisal of symptoms.

People with respiratory symptoms were most commonly coded as re-appraising their symptoms (n = 9 quotes from 5 (10%) participants), followed by one participant each for oral (n = 2 quotes), colorectal (n = 2 quotes) and pancreatic (n = 2 quotes) symptoms. *Re-appraisal of* symptoms was not mentioned amongst people melanoma, breast and prostate symptoms.

For many participants *re-appraisal of symptoms* seemed to be a recurring process. Specifically, individuals tended to re-evaluate their coping methods if a certain procedure was ineffective. Many noted that they sought help from a HCP about their symptoms who then prescribed medication. The prescribed medication appeared to alleviate symptoms temporarily. However, symptoms usually came back which in turn caused individuals to seek help again.

> *"I went home and started taking them and normally with antibiotics you feel the, you know, almost immediate benefit, but in this case I didn't, so I made another appointment for the, this was, I went, initially went on Friday, I went again I think it was a Monday"* [Res1, Respiratory, Female, 68 years, Shortest TTP]
>
> **"And do you think that was significant that you went back to the GP and...?"**
> *"Yeah, and I thought... Because when the steroids worked and then it started coming back, I kept thinking... People would say, oh you're still coughing. I just said, oh it's just a cough, it's like a cold. And you're thinking, perhaps it is just a cold this time and I'm making it up or something. But then when it carries on you realise that you probably are quite ill."* [Res6, Respiratory, Female, 42 years, Longest TTP]

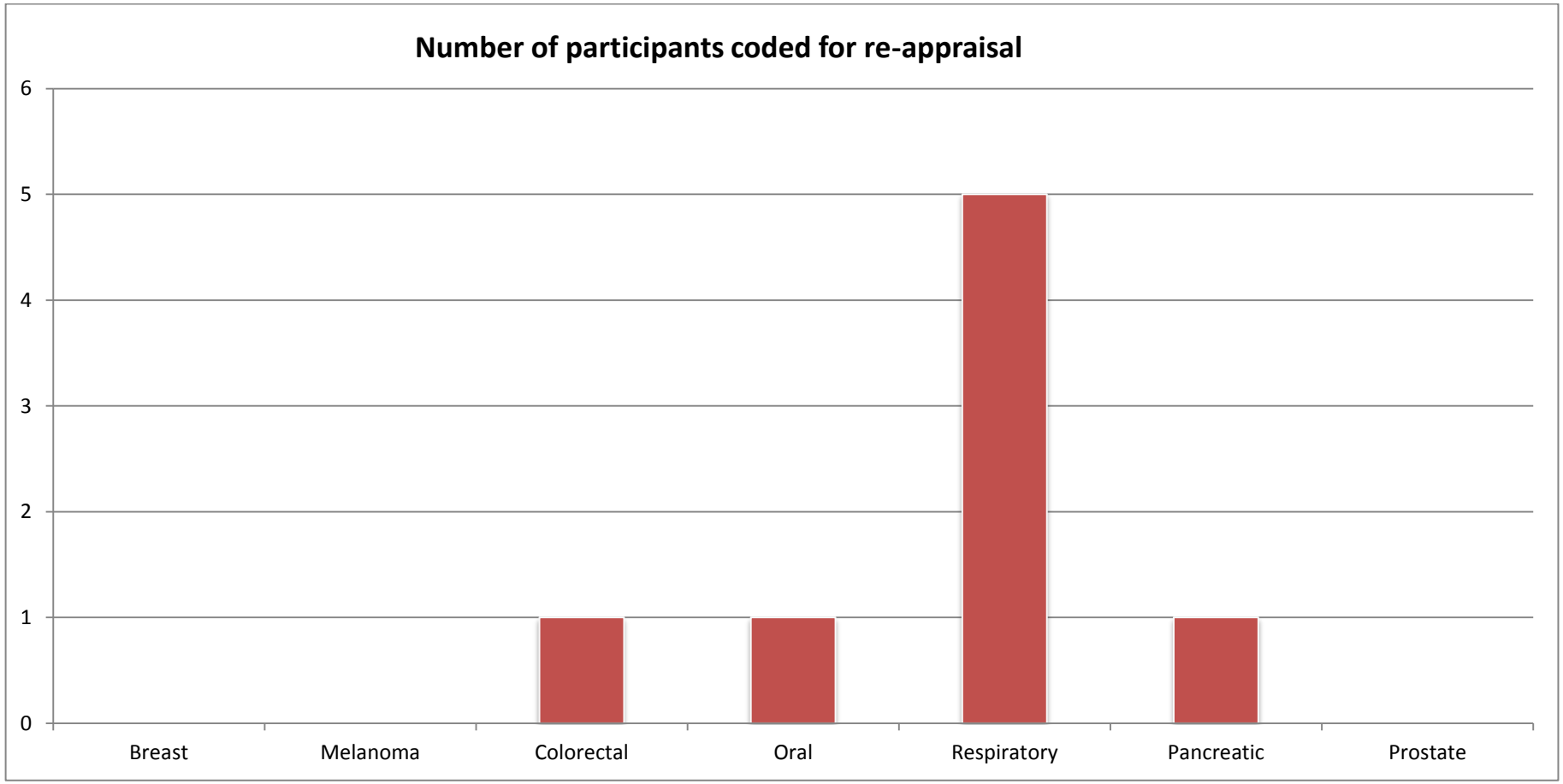

Figure 13 Number of participants coded for re-appraisal

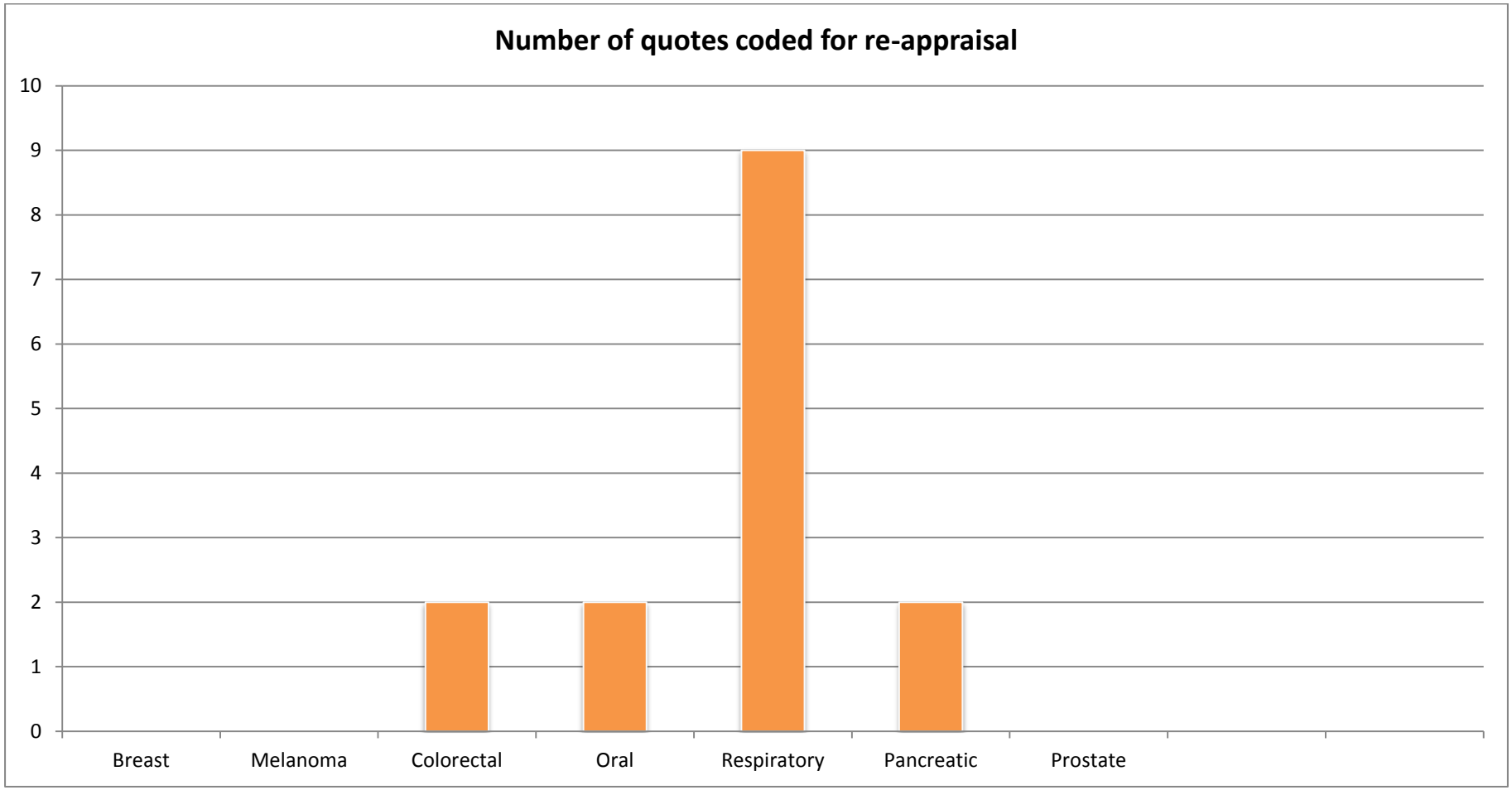

Figure 14 Number of quotes coded for re-appraisal

3.5.2.2 Reasons and lack of reasons to consider discussing symptoms with a HCP

Figure 15 demonstrates the number of participants coded as having reasons to consider discussing symptoms with a HCP. **Figure 16** demonstrates the number of quotes coded for reasons to consider discussing symptoms with a HCP.

Cognitive Factors (n = 46 quotes from 26 (53%) participants), followed by *perceived inability to cope with symptoms* (n = 26 quotes from 16 (33%) participants) and social influences (n = 23 quotes from 15 (31%) participants) were given as the most predominant reasons to consider discussing symptoms with a HCP. *Consequences of symptoms* (n = 24 quotes from 17 (35%) participants) and *emotional factors* (n = 16 quotes from 10 (20%) participants) were the least prevalent reasons to consider discussing symptoms with a HCP.

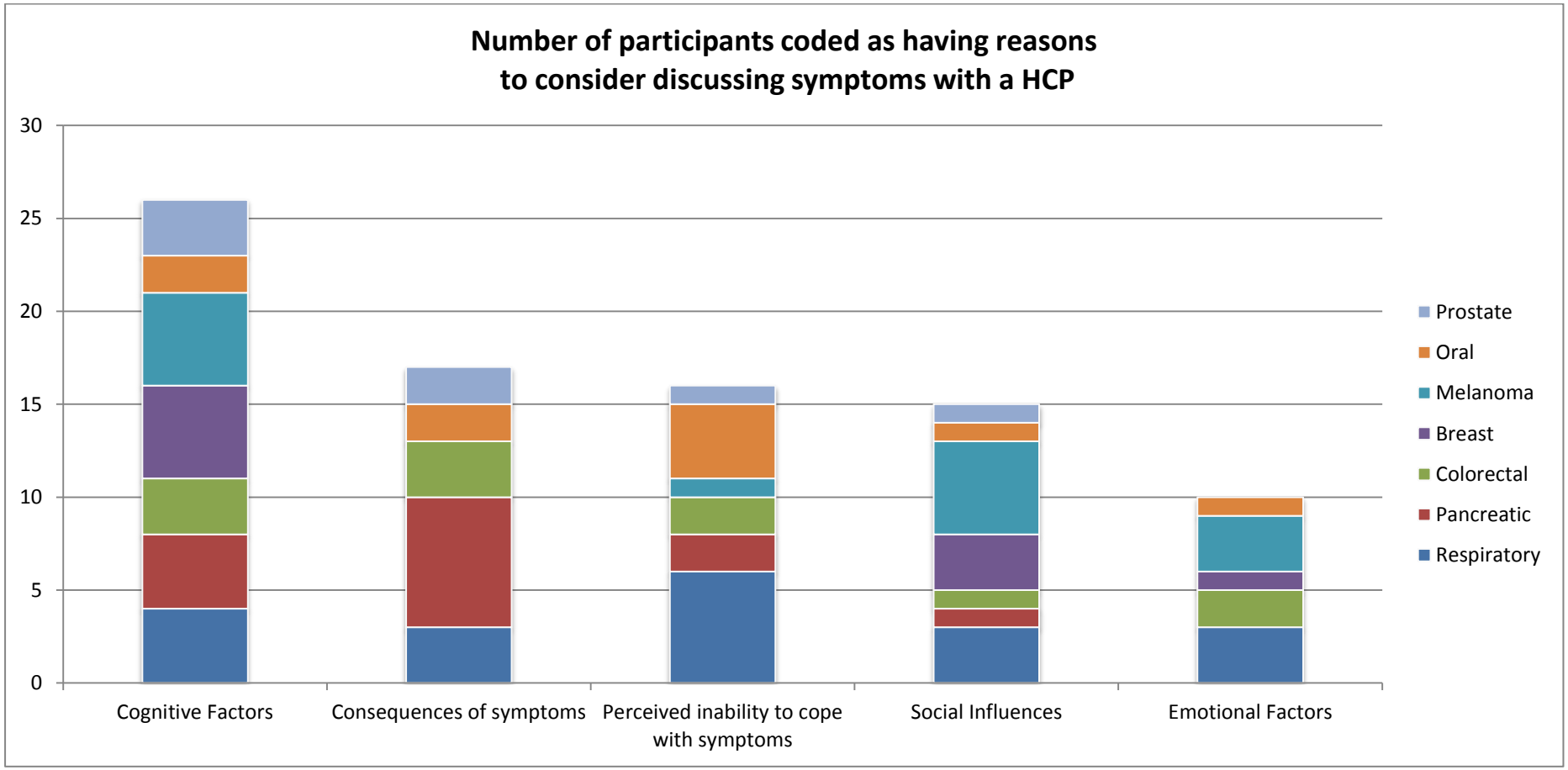

Figure 15 Number of participants coded as having reasons to consider discussing symptoms with a HCP

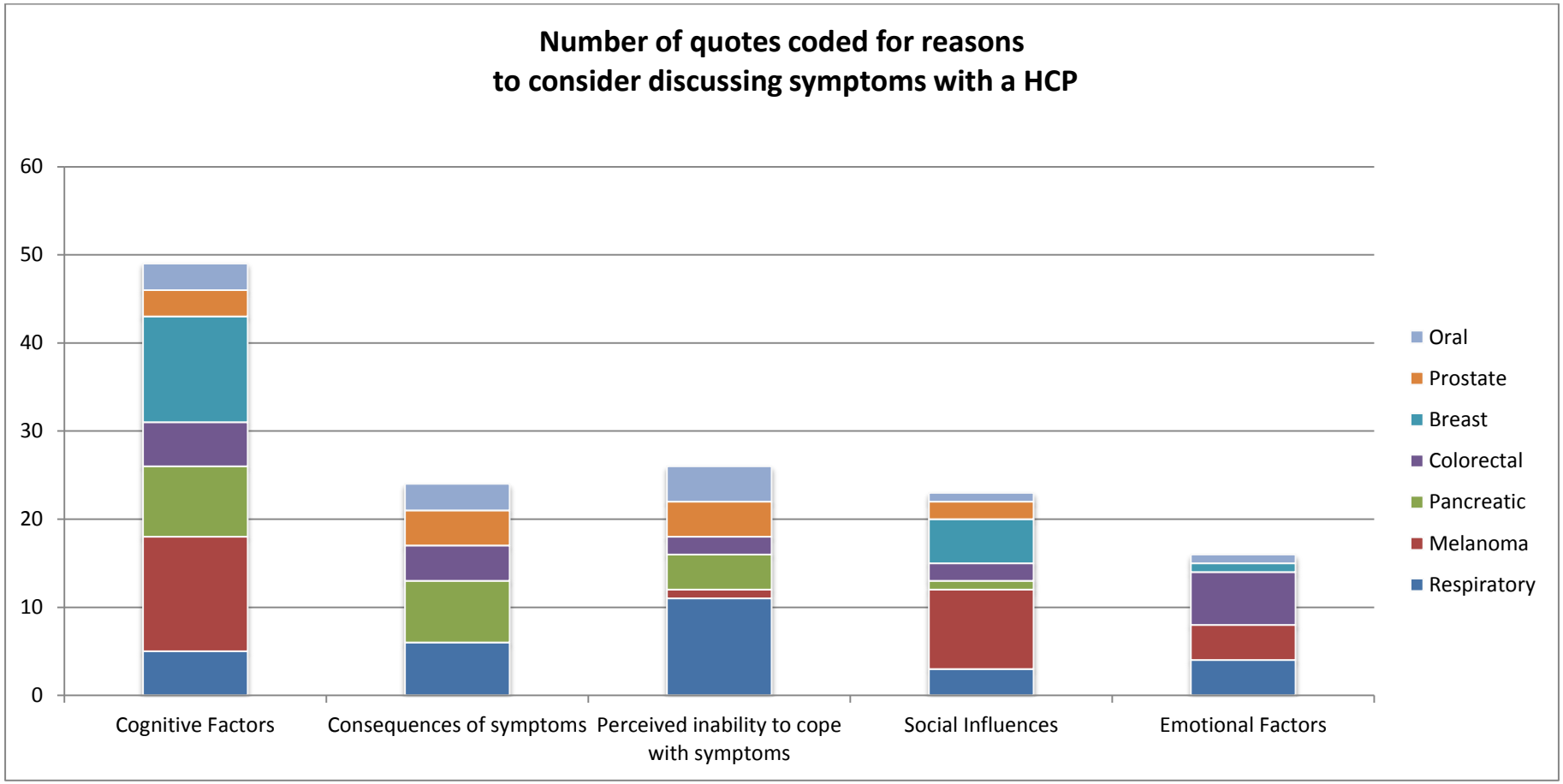

Figure 16 Number of quotes coded for reasons to consider discussing symptoms with a HCP

Figure 17 demonstrates the number of participants coded for reasons not to consider discussing symptoms with a HCP. **Figure 18** demonstrates the number of quotes coded for reasons not to consider discussing symptoms with a HCP.

The most prevalent reasons not to consider discussing symptoms with a HCP to which people referred to were *cognitive factors* (n = 25 quotes from 13 (27%) participants) followed by *emotional factors* (n = 10 quotes from 5 (10%) participants), *perceived ability to cope with symptoms* (n = 5 quotes from 4 (8%) participants) and *no consequences of symptoms* (n = 3 quotes from 3 (6%) participants). *Social influences* were not mentioned by participants as a reason not to consider discussing symptoms with a HCP.

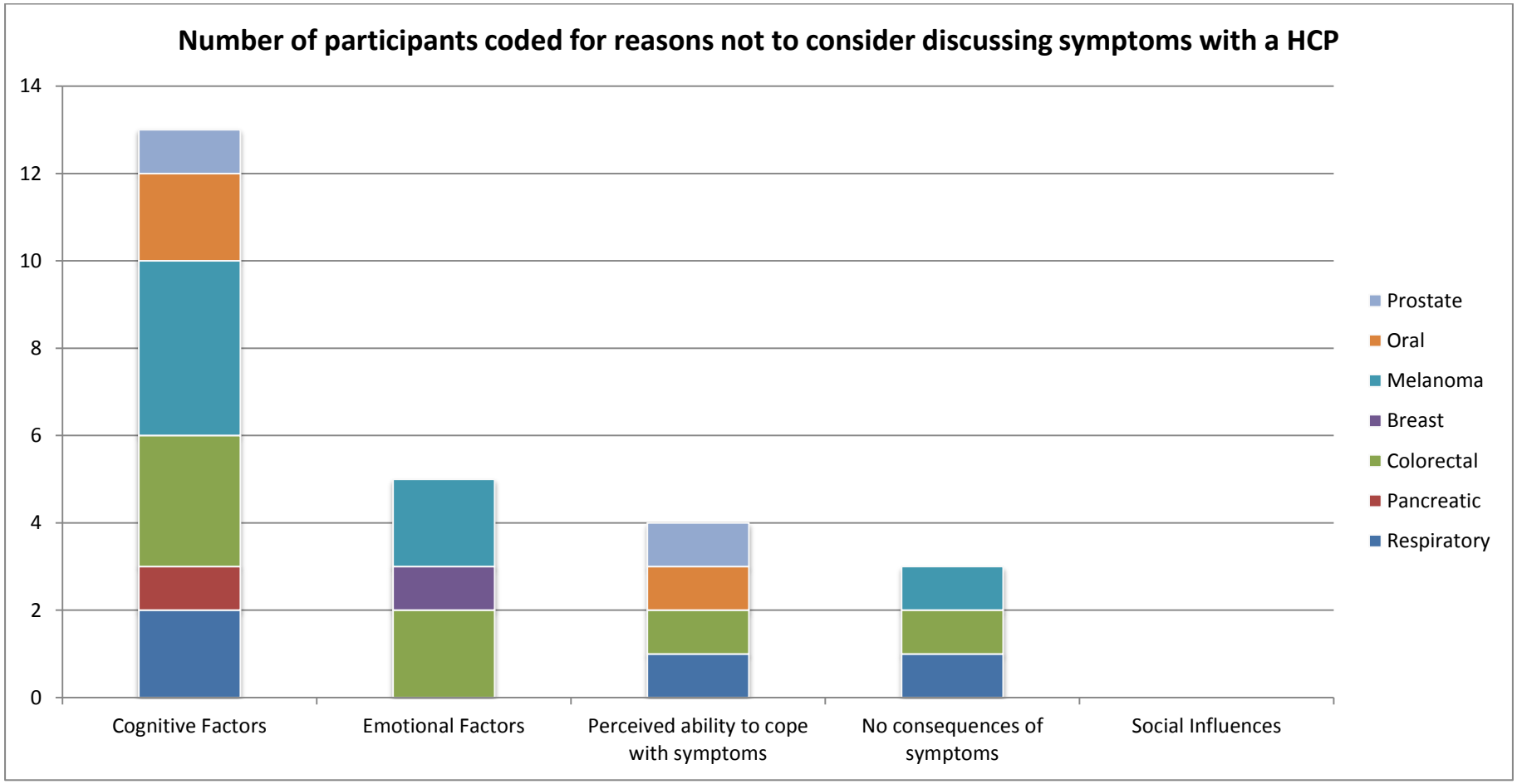

Figure 17 Number of participants coded as not having any reasons to consider discussing symptoms with a HCP

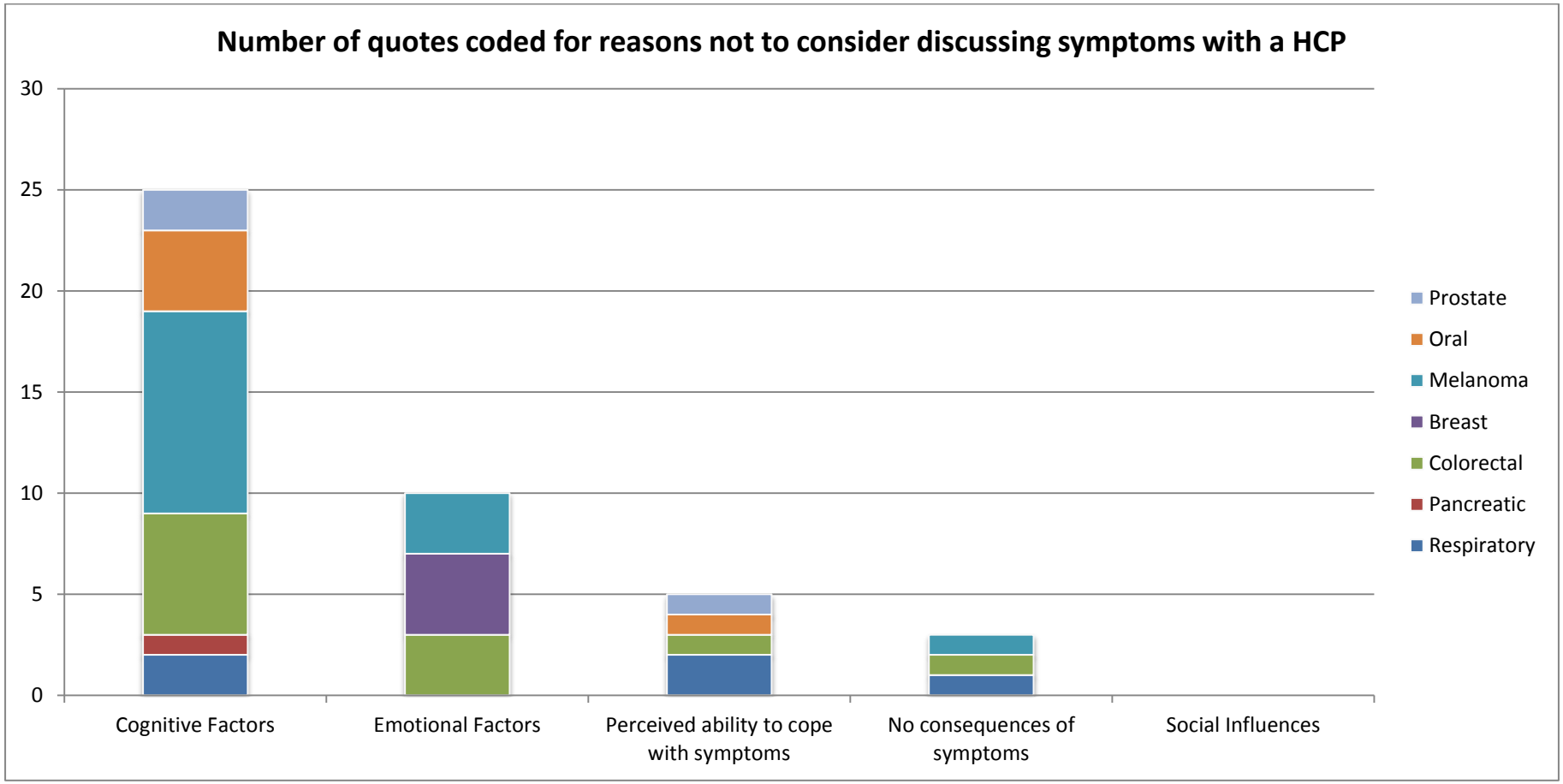

Figure 18 Number of quotes coded for reasons not to consider discussing symptoms with a HCP

Illustrative quotes of the reasons and lack of reasons to consider/ wish to discuss symptoms with a HCP are further outlined and explained below to demonstrate how cognitive factors, (no) consequences of symptoms, perceived (in)ability to cope, (no) emotional factors and (no) social influences frequently influenced the perceived need to discuss symptoms with a HCP.

3.5.2.2.1 Cognitive Factors

Participants talked about how cognitive factors, such as their beliefs about symptoms, or that something is wrong or serious, were often seen as reasons to consider help-seeking. *Cognitive factors* were coded as reasons to consider discussing symptoms with a HCP across all groups, most frequently by those with melanoma (n = 5), breast symptoms (n = 5), respiratory (n = 4) or pancreatic symptoms (n = 4).

As demonstrated by the illustrative quotes in **Table 32**, participants had different ways of expressing their cognitive reasons for considering seeking help. The various ways in which people expressed help-seeking could be grouped into four categories, namely: 1) not right or something is wrong, 2) something is not normal or is odd or different, 3) something is serious or not good and 4) needing help or requires sorting.

Just as beliefs about symptoms prompted consultation with a HCP, *cognitive factors* were coded as reasons not to consider discussing symptoms with a HCP by all groups, most commonly by people with melanoma (n = 4), followed by people with colorectal (n = 3), respiratory (n = 2) and oral (n = 2) symptoms.

> *"there never was enough like, I thought, 'no, it's nothing serious, I don't need to go and see doctor', even people asked me about it because as it's on the leg and on the part of the leg where people can see, sometimes people ask, 'have you seen a doctor?', and many time, and I always said, 'no, it's just one of the spots I have on my skin so I don't need a doctor, I don't need, I feel healthy'."* [Mel 6, Melanoma, Female, 40 years, Longest TTP]

> *"…and I just kind of really just thought oh it's going to go away, it's not you know [serious]…"* [Or7, Oral, Female, 50 years, Longest TTP]

Table 32 Illustrative quotes demonstrating participants' different ways of expressing cognitive reasons for considering help-seeking

Different ways of expressing considered help-seeking	Examples of illustrative quotes
Not right or something is wrong	*"I knew there was something that just weren't right"* [Pa3, Pancreas, Female, 53 years, Median TTP] *"that doesn't look right"* [Or9, Ora, Male, 51 years, Shortest TTP] *"look, this isn't right"* [Pa4, Pancreas, Male, 79 years, Median TTP] *"it just really isn't right"* [Mel2, Melanoma, Female, 54 years, Shortest TTP] *"there's something wrong"* [Pa1, Pancreas, Female, 59 years, Shortest TTP] *"I thought there was something wrong"* [Pr3, Prostate, Male, 65 years, Median TTP] *"I thought something could be wrong"* [Pr5, Prostate, Male, 82 years, Longest TTP] *"there is something wrong"* [Br4, Breast, Female, 56 years, Median TTP] *"There's something wrong here"* [Res5, Respiratory, Female, 74 years, Longest TTP] *"there must be something wrong"* [Res6, Respiratory, Female, 42 years, Longest TTP]
Something is not normal, or is odd or different	*"I decided that I thought it was something odd"* [Mel5, Melanoma, Male, 72 years, Longest TTP] *"it's not normal"* [CRC5, Colorectal, Female, 67 years, Longest TTP] *"something's going on that shouldn't be and I started to be a bit suspicious"* [CRC5, Colorectal, Female, 67 years, Longest TTP] *"That hurt, that hurt's not normal"* [Br4, Breast, Female, 55 years, Median TTP] *"this just felt abnormal, so ... I'd better go and get it checked out."* [Br1, Breast, Female, 49 years, Shortest TTP] *"I knew it wasn't normal"* (Breast - Female, median TTP, under 60) *"I don't like the look of this mole now"* [Mel2, Melanoma, Female, 54 years, Shortest TTP]
Something is serious or not good	*"this is getting to be a bit more serious."* [Or7, Oral, Female, 50 years, Longest TTP] *"this is getting really serious now"* [Or7, Oral, Female, 50 years, Longest TTP] *"That's really not good"* [Mel4, Melanoma, Female, 36 years, Median TTP] *"I knew it wasn't good."* [Mel4, Melanoma, Female, 36 years, Median TTP] *"it bleeding was not a good sign"* [Mel4, Melanoma, Female,

Different ways of expressing considered help-seeking	Examples of illustrative quotes
	36 years, Median TTP] *"So I thought, well this isn't good, there's something I need to get looked"* [Pa1, Pancreas, Female, 59 years, Shortest TTP] *"I might be in a bit of trouble"* [Pa4, Pancreas, Male, 79 years, Median TTP]
Needing help or requires sorting	*"need to get it sorted out"* [Mel7, Melanoma, Male, 48 years, Shortest TTP] *"it's got to be sorted"* [Mel7, Melanoma, Male, 48 years, Shortest TTP] *"I've really got to get something done about it."* [Or7, Oral, Female, 50 years, Longest TTP] *"It's now become a medical issue"* [Or7, Oral, Female, 50 years, Longest TTP] *"it is slightly different to everything else, it is now slightly inflamed and raised, let's do something about it."* [Mel8, Melanoma, Female, 63 years, Longest TTP] *"I can't manage it"* [Pa1, Pancreas, Female, 59 years, Shortest TTP]

3.5.2.2.2 (No) Consequences of Symptoms

Consequences of symptoms were frequently a trigger to seek help for participants across those with pancreatic (n = 7), respiratory (n = 3), colorectal (n = 3), oral (n = 2) and prostate (n = 2) symptoms. However, for individuals with breast symptoms or melanoma, there was no evidence of the *consequences of symptoms* acting as a prompt to consult a HCP.

Participants mentioned numerous consequences of symptoms as a motivation for seeking help. This seemed to vary between groups. For example, participants presenting with pancreatic and oral symptoms spoke about how bodily changes had an impact on their diet and eating behaviour, noting that a loss of appetite, weight loss and not being able to eat (properly) was common.

On the other hand, people with colorectal symptoms mentioned how urgent bowel movements interfered with their day to day lives.

> *"Well it did because I daren't go far, yeah. I mean, like going up Tesco's you'd drop pads in your pants and rush to the loo up there and then 'will I get home', yes, so..."* [CRC6, Colorectal, Female, 71 years, Shortest TTP]

Conversely, when symptoms had no consequences this acted as a barrier to help seeking for one individual each with melanoma, respiratory and colorectal symptoms. For example, one individual with respiratory symptoms highlighted that she did not consider seeking help, because she experienced no impact of symptoms.

> *"Never felt breathless. I never felt unwell and I never felt breathless. Which was why I you know didn't get worked up about it really."* [Res3, Respiratory, Female, 56 years, Median TTP]

3.5.2.2.3 Perceived (in)ability to cope with symptoms

Perceived inability to cope with symptoms was most commonly mentioned as a reason to consider help-seeking amongst people with respiratory (n = 6, number of quotes = 11) and oral symptoms (n = 4, number of quotes = 4). There was no support for *Perceived inability to cope with symptoms* influencing help-seeking for individuals presenting with breast symptoms.

During the appraisal interval many participants tried to self-manage their symptoms using over the counter (OTC) medication or medication prescribed by their doctor, but when this failed to resolve symptoms, people re-appraised the need for care.

> *"Anyway, continued on the medication and finished it and within about three days of coming off it all my symptoms came back up again."* [Pa1, Pancreas, Female, 59 years, Shortest TTP]

On the contrary, one participant each amongst people with respiratory, oral, colorectal and prostate symptoms cited *perceived ability to cope with symptoms* as a reason not to consider discussing symptoms with a HCP. The urgency to seek help was reduced when participants were able to self-manage their condition with over the counter medication.

> *"Whatever I bought I can't remember. And it definitely made a difference, made it easier."* [Res3, Respiratory, Female, 56 years, Median TTP]

3.5.2.2.3.1 Emotional factors and (not) considering help-seeking

Emotional factors were noted as a reason to consider discussing symptoms with a HCP amongst people with melanoma (n = 3) and respiratory symptoms (n = 3), and to a lesser extent amongst people with colorectal (n = 2), breast (n = 1) and oral (n = 1) symptoms.

Emotional factors were not mentioned as reasons to consider help-seeking behaviour amongst people with pancreatic and prostate symptoms.

Persisting symptoms or symptom progress caused participants to worry and as such they often began considering seeking help.

> *"I mean, the very first time when I saw the other doctor, I think I was more worried about the actual fluey thing, because it came so suddenly, but I did make a point of mentioning the cough since Christmas, I said 'You know, that's what's really worrying me as much as anything, but this coming on top of it has just prompted me to get myself in here'."* [Res5, Respiratory, Female, 74 years, Longest TTP]

> *"And then at the top part it got a little bit darker. And I went to see my doctor, I was a bit worried then because my boy at 40 he had a melanoma on his arm and at 50..."* [Mel3, Melanoma, Male, 84 years, Median TTP]

On the contrary, one participant was not concerned about their symptoms. They explained that this was, because they thought their symptoms were fleeting.

> ***"Did you have time to make a doctor's appointment before you went on holiday, or had too much to do?"***
> *"No, I think I made it when I came back. That's how worried I was."*
> ***"Yeah, fine."***
> *"It was just, 'Oh well, well,' you know, 'it might be a pimple that's gone down by the time I get home'."* [Mel8, Melanoma, Female, 63 years, Longest TTP]

3.5.2.2.3.2 Social Influences

Social Influences were regarded as a reason to consider discussing symptoms with a HCP across all groups, especially for participants with melanoma (n = 5). For example, in participants with melanoma participants were often encouraged by others, such as friends or family members to seek help, because their skin change was noticed by another person.

"[Wife]*I told you to go, yeah.*
…you told me, but I wouldn't have bothered for another few days actually, I think, you know." [Mel1, Melanoma, Male, 82 years, Shortest TTP]

"So we think it was probably then that I went probably went round for a coffee and she said "oh that's rather dark and that's rather large and you probably ought to go and have it looked at it" [Mel4, Melanoma, Female, 36 years, Median TTP]

This is similar to individuals who presented with breast symptoms (n = 3) as a result of individuals asking their partner whether they could feel a lump or mass in their breast.

3.6 Discussion

This study explored whether the accounts of the decision to seek help given by patients with malignant or potentially malignant symptoms could be classified according to contributing factors [constructs of the CSM (Leventhal et al., 1984)] within the appraisal interval of the MPT (Scott et al., 2013). The MPT provided a useful framework within which to investigate and understand the factors that contribute to patients' appraisal of symptoms and decision to seek help that were documented in existing qualitative data. This study has helped to further validate the MPT and classifying the responses according to the contributing factors has also allowed insight into which contributing factors may be most prominent in the accounts of appraisal. Further, this study has identified the ways in which each factor is referred to, which has since helped to contribute to the generation of items for the PaTH-Q (see Chapter Four).

Even though there was support for all elements within the appraisal interval of the MPT, findings from the study particularly revealed use of cognitive heuristics to interpret symptoms and decide whether these symptoms require medical care. The *Rate of Change rule*, *Symmetry rule* and *Duration rule* were particularly prominent heuristics guiding symptom interpretation and the perceived need to seek help. There was also support for the other heuristics, apart from the *Stress-Illness rule* and the *Prevalence rule*. Whether this is because these are less applicable to the interpretation of potentially malignant symptoms, or whether they are less well articulated may need further investigation. There

is a dearth of research into the influence on psychological heuristics on symptom interpretation.

As part of the development and application of the categorisation matrix, alterations were required to some of the existing definitions of the heuristics constructs as noted by Scott et al. (2013). It was found that some of the definitions of heuristics influencing the interpretations of symptoms needed further clarification, or were not mutually exclusive and so were combined. This has implications for future use and operalisation of the heuristics and adds to the development and application of theory.

The CSM (Leventhal et al., 1984) proposes that experiencing bodily changes or symptoms will trigger comparisons to illness schema stored in memory (Cameron & Moss-Morris, 2004) which enables an individual to match their symptom experience. Consequently, if a symptom matches or is similar to an individual's existing illness schema it will be more likely that a symptom will be interpreted as (an indicator of) a disease and as a result of this the decision to consult a HCP will often be chosen as a coping procedure (should that be the believed way of coping). However, the results from the present study revealed that individuals do not specifically form illness representations about cancer. Instead there were more general cognitive representations that drove or delayed the decision to seek help. Findings from this study indicated that individuals also had different ways of expressing cognitive reasons for considering help-seeking which could broadly be grouped into four different categories, namely: 1) something is not right or something is wrong, 2) something is not normal, odd or different, 3) something is serious or not good, and 4) something needs help or requires sorting. Individuals' different ways of expressing considered help-seeking suggest that it appears having a specific illness label may not be an essential precursor to seeking help. Rather an individual's awareness that something is wrong, not normal or something is serious may be a sufficient enough prompt to initiate help-seeking behaviours.

Participants' ability to cope also contributed to their perceived decision to consult a HCP. Particularly, in individuals with oral, respiratory, colorectal and pancreatic symptoms perceived ability to cope was often cited as a reason not to consider seeking help. These individuals cited that (self) medication was frequently used to help them cope with their symptoms. Further, it appeared that in individuals with respiratory and oral symptoms this perception only shifted once symptoms failed to resolve with the help of medication. These

findings are supported, for example, by the work of Birt et al. (2014) who revealed that ineffective self-management techniques frequently encouraged decision to seek help for individuals with symptoms suspicious of lung cancer.

Consequences of symptoms were associated with a perceived reason to seek help amongst individuals with pancreatic, respiratory and colorectal symptoms, whereas there was no indication of this among individuals with symptoms of melanoma and breast, something which may be due to the varying symptomatology between different illnesses. In individuals with melanoma and breast symptoms the perceived reason to seek help was often attributed to cognitive, social and emotional factors.

Findings also indicated that social factors only appeared to be a prominent reason to consider seeking help when family or friends became aware of participants' symptoms and encouraged them to consider consulting a HCP. Individual's social network has shown to be an important factor in reassuring and prompting individuals to consider seeking help for their symptoms in a variety of studies (Burgess et al., 2001; Gascoigne, Mason, & Roberts, 1999; Marlow, McGregor, Nazroo, & Wardle, 2014).

With regard to coping procedures, individuals appeared to engage in numerous approaches. A few individuals with breast, melanoma, colorectal, prostate and oral symptoms noted that they dismissed or ignored their symptoms. The usage of self-medication was especially frequent amongst individuals with respiratory, pancreatic, colorectal and oral symptoms. Similar findings have been reported by Elliott et al. (2011) who investigated the use of different symptom management techniques for various symptoms in a sample of 8 000 UK adults and found that the most common response to symptoms was to do nothing, followed by self-medicating. Moreover, re-appraisal of symptoms was also more common in these groups. Re-appraisal might have been more frequent in these groups as individuals who used self-medication as a coping procedure might have realised that their medication failed to alleviate symptoms which ultimately led to the re-appraisal of the coping procedure or illness/symptom representation. This is in line with previous assumptions by Diefenbach and Leventhal (1996) who noted that coping procedures and re-appraisal of symptoms are not a uni-directional process but rather a dynamic one. Moreover, even though all cancer groups used symptom monitoring as a coping procedure this procedure was most frequently noted amongst individuals with melanoma. It could be argued that individuals with melanoma and breast symptoms were

more likely to monitor their symptoms due to the presence of palpable, visible or noticeable symptoms (Lyratzopoulos et al., 2015). Leventhal et al. (1980) argue that concrete signs play a critical role in determining the relationship between illness representations and coping because by monitoring symptoms individuals are able to appraise their current illness state. For example, doing so will allow them to determine if their condition is getting worsening or improving, or if it is changing or not.

On the whole, participants showed little emotional response in relation to their symptoms. For example, individuals revealed that they were often not anxious, worried or concerned about their bodily changes. If an emotional response such as worry, anxiety or fear was experienced this was usually due to the striking nature of symptoms. The absence of a severe emotional response is in line with other research. For example, a systematic review by Balasooriya-Smeekens et al. (2015) found that emotions (e.g. being afraid, scared, distressed or angry as well as fear) in response to symptom discovery had no significant relationship with TTP. Only worry or anxiety about the symptom or lesion was linked to shorter TTP. Further, the authors also discovered that non-specific emotions (e.g. worry, fear or concern) had no significant relationship with TTP. Rather, only specific emotions such as fear of cancer diagnosis, fear of cancer treatment and fear about implications were linked to a longer TTP. However, this seemingly overall lack of emotional response in relation to symptom interpretation, as found in this study and by Balasooriya-Smeekens et al. (2015) may be problematic, because without an emotional reaction the prompt to seek help in a swift manner may not occur.

3.6.1 Strengths

There are a number of strengths to this study. The findings may be broadly generalisable as data were analysed from individuals with symptoms of seven different types of cancer (oral, melanoma, breast, prostate, lung, pancreatic and colorectal) and recruited across two different countries (United Kingdom and Australia). Analysing data across a diverse group allowed comparisons to be made across individuals' accounts of the appraisal of symptoms, such as whether people with different cancer types interpret symptoms differently or how they interpret symptoms.

This secondary analysis followed Hinds et al.'s (1997) guidance on secondary analysis by ensuring the following. First, even though the research questions were not identical, both the original studies and the current study looked at factors contributing to patients'

appraisal of symptoms and their decision to seek help. Second, while the data analyses were not identical to the original studies, the IRCO study, the SYMPTOM study and the Melanoma interview study used the MPT to underpin their data collection and analysis. Third, although Hinds et al.'s (1997) assessment tool was only applied in a cursory manner, when doing so it indicated that the quality of the primary study datasets was good. It is believed that if there were any quality issues with the datasets then these would have been noted by the researcher when analysing and interpreting the data, or by the researcher's supervisors who analysed one transcript from each cancer type.

Coding the data with the help of a pre-determined coding framework enabled data to be analysed in a systematic manner, ensuring that themes were mapped onto a theoretical framework. This approach not only enabled further validation of the MPT (Scott et al., 2013) but also enabled existing theory to be further supported, refined and extended. Scott et al. (2013) noted that the there is some supportive evidence for the model due to an overlap with the Andersen Model and some existing research that has used the MPT (e.g. Birt et al., 2014), yet none of the studies to date have directly investigated whether there is support for the CSM (Leventhal et al., 1984) within the MPT (Scott et al., 2013). Systematic mapping of contributing factors of patients' appraisal of symptoms using a theoretical model enabled to determine the relevance of the theory and highlight which factors may be most important. Findings from this secondary qualitative analysis suggest that heuristics play a dominant role in individuals' appraisal of symptoms and subsequent help-seeking behaviour, and that this may vary between different symptoms/cancer types. For example, while there was evidence for the use of 11 of the 13 different heuristics with those with melanoma, yet those with breast symptoms only demonstrated the use of 7 of the 13 heuristics, with no evidence of the *Chronology rule*, *Duration rule*, *Severity rule*, or *Similarity rule*. This may be due to variations in the ambiguity of symptoms between these cancer types. *Optimistic Bias rule* was evident in those with prostate, breast, and melanoma symptoms but not those with pancreatic, oral, respiratory, or colorectal symptoms. These potential differences could be further investigated in future studies to inform the need and content of cancer-specific interventions. Furthermore, quantitative measurements are also required for more rigorous hypothesis testing. Consequently, the findings from this study were used to inform the item generation for a theory-based questionnaire, the PaTH-Q.

3.6.2 Weaknesses

In all studies, participants were recruited shortly before or after diagnosis, therefore reducing recall bias. Despite this approach, all studies used a retrospective design and therefore it may still be possible that individuals failed to accurately recall symptoms, thought processes, behavioural response or symptom interpretation after the passage of time and beginning treatment for a major illness.

It can be argued that coding the data with the help of a pre-determined categorisation matrix may have biased the exploratory nature of qualitative analysis as categories related to the theoretical construct may have been actively searched for, in addition to disregarding potentially unrelated categories. However, further consideration of the data suggests that while themes could have been classified differently, the issues still emerged and have been described as they relate to the different elements of the model. For example, individuals deciding something must be done once symptoms persisted over a prolonged period or if symptoms got worse. Moreover, to ensure that all likely occurrences of the phenomenon were captured, data that were not coded initially was identified as 'other' and analysed at a later stage to determine whether it could be coded within an existing category or if it represented a new category. Furthermore, cases that were not supportive of the theory were actively searched for and reported when found.

Hinds et al. (1997) have noted that one of the methodological challenges of secondary analysis is the difference in the research question between the primary study and that of the secondary analysis. However, even though the aim of the present study differed slightly to those for which the data were originally collected for, the current study still examined patients' appraisal and help-seeking behaviour for [potential] symptoms of cancer.

Finally, it is acknowledged that some heuristics definitions were missed when developing the categorisation matrix and coding the data. For example, further reading of the literature revealed the existence of one more heuristic, namely the *Conservation rule* which notes that older adults may shift symptom evaluation and decision-making onto healthcare professionals in order to avoid placing a burden on their own limited cognitive and physical energy (Martin et al., 2003). Nevertheless, as highlighted previously prior to coding the data it was decided that data which did not fit existing categories within the categorisation matrix would be coded as 'other' so as to make certain that all expressions were recorded,

and no support for the *Conversation rule* was found in categories that were coded as 'other'.

3.6.3 Conclusion

Findings from this study revealed that the appraisal interval was predominantly influenced by psychological heuristics that people can use to interpret symptoms and decide whether these symptoms require medical care. Consequently, the findings provide insight into the elements in symptom appraisal that may in turn trigger or prevent help-seeking behaviour. To date there has been as a lack of research into the influence on psychological heuristics on symptom interpretation, yet findings from current research indicate that these heuristics may underlie symptom interpretation and, importantly, misinterpretation, thus making them key targets for interventions.

Chapter 4 : The Development of the Pathways to Healthcare Questionnaire (PaTH-Q): Content and Face Validation

4.1 Introduction

The secondary analysis outlined in Chapter Three offered a preliminary insight into how heuristics and 'cognitive reasons to consider help-seeking' might influence symptom interpretation and guide help-seeking behaviour. This chapter describes the process of developing a questionnaire (the PaTH-Q) to measure these constructs. The overarching objective of the studies presented within this chapter was to have developed PaTH-Q items with satisfactory content and face validity. This chapter is structured around several main steps undertaken as part of the development process (see **Figure 19** for a summary). Each main development phase is accompanied by a specific set of aims which are outlined in their respective sections below.

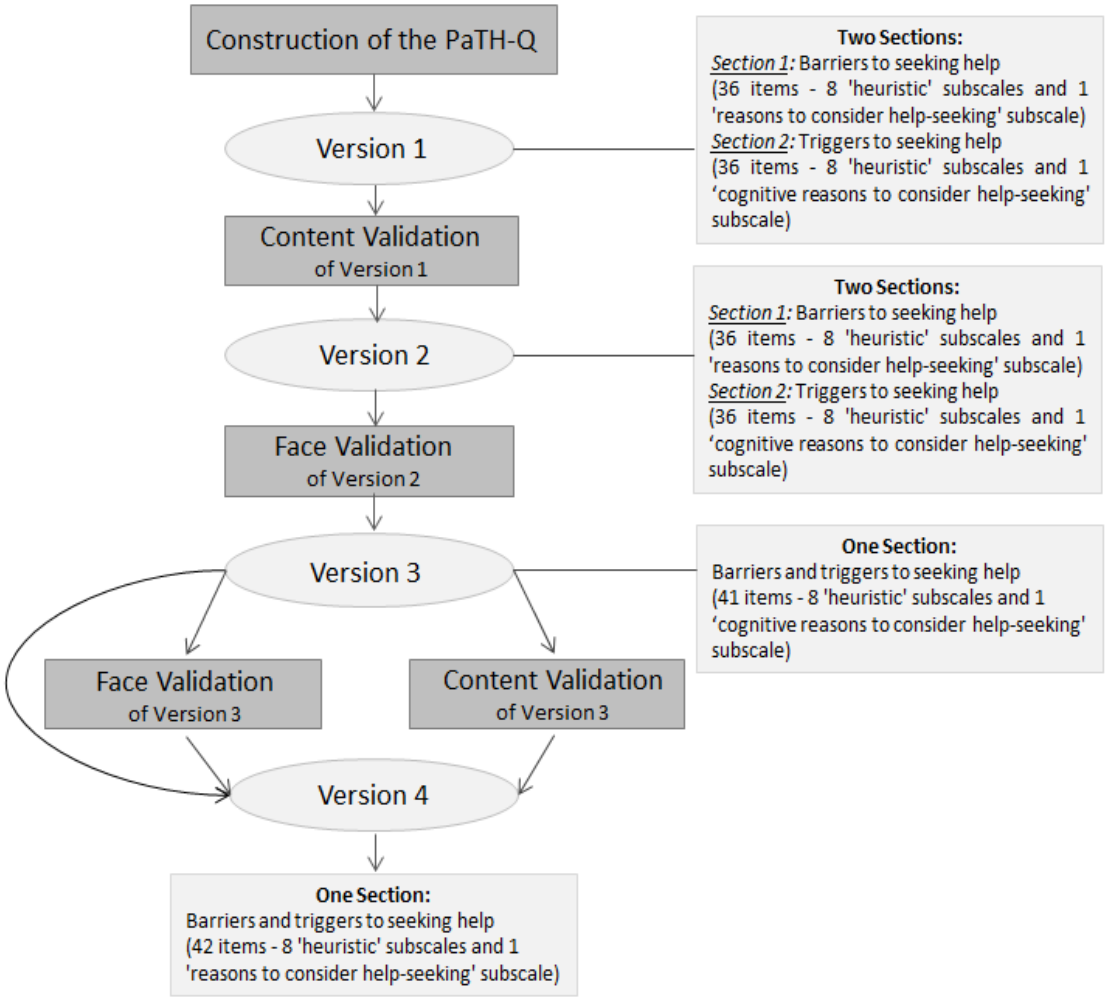

Figure 19 Development process of the PaTH-Q

4.2 Construction of the PaTH-Q: Development and rationale

As noted in Chapter One the importance of theory should not be underestimated as it enables researchers to build on existing knowledge as well as enabling hypotheses to be generated. Similarly, using theory to underpin the questionnaire development provides guidance on what variables should be measured (Noar & Zimmerman, 2005), how these variables are likely to interact, and provides definitions for each variable. Theory-based questionnaires enable the operationalisation of psychological theory.

The development of the PaTH-Q was guided by the MPT (Scott et al., 2013) because the model provides a theoretical framework for studies investigating the pathways to cancer diagnosis. Specifically, the MPT encompasses the events, processes and intervals that may take place from symptom appraisal through to medical treatment and also identifies a range of factors that might contribute to the duration of each interval. The MPT proposes that existing psychological theory, specifically the CSM (Leventhal et al., 1984) can help to identify the various contributing factors within the appraisal interval.

There are many behavioural and decisional processes outlined in the CSM that occur within the appraisal interval (for instance emotional response to symptoms or coping procedures such as self-treatment or monitoring symptoms), and it would be impossible to measure all of these in one questionnaire. Furthermore, some variables postulated in the MPT/CSM can be measured with existing questionnaires for instance the 'Symptom Distress Scale' by (Meechan et al., 2003). Following the findings from the systematic review (Chapter Two) and secondary analysis (Chapter Three) it was decided that a new questionnaire (the PaTH-Q) was needed to focus on heuristics [which are an element of the CSM as further outlined on pages 142 to 143] and 'cognitive reasons to consider help-seeking' as these variables appear to be key in help-seeking behaviour, yet currently lack adequate measures. For instance, even though findings from the systematic review (Chapter Two) revealed that measures which focus on 'symptom interpretation', these measures have mainly focused on the cause or attribution of symptoms and as such do not consider the full range of cognitive reasons to seek help or the processes involved in appraising symptoms, plus existing measures lacked evidence of reliability and or validity.

Figure 20 illustrates how heuristics and 'cognitive reasons to consider help-seeking' fit into the MPT. Heuristics and 'cognitive reasons to consider help-seeking' are closely related. It is, however, important to make a distinction between the two concepts. Heuristics are

assumed to precede 'cognitive reasons to consider help-seeking'. Heuristics are defined as a psychological rule of thumb which help individuals to appraise their symptoms (part of the process within appraisal interval of the MPT) whereas 'cognitive reasons to consider help-seeking' are a possible outcome of that appraisal. 'Cognitive reasons to consider help-seeking' are a cognitive representation of the threat (an element of illness representations) that is specifically about the perceived need for seeking help, and mark the event at the end of the appraisal interval. Of course, as specified in the MPT/CSM, there may be other perceived reasons for seeking help, for instance consequences of symptoms (e.g. inference of symptoms with one's ability to work), perceived inability to cope with symptoms (e.g. persistence, symptom salience, failure to self-medicate) and emotional factors (e.g. anxiety, concern, need for reassurance), but the PaTH-Q will solely focus on the cognitive reasons (beliefs about symptoms, for example something is serious/wrong).

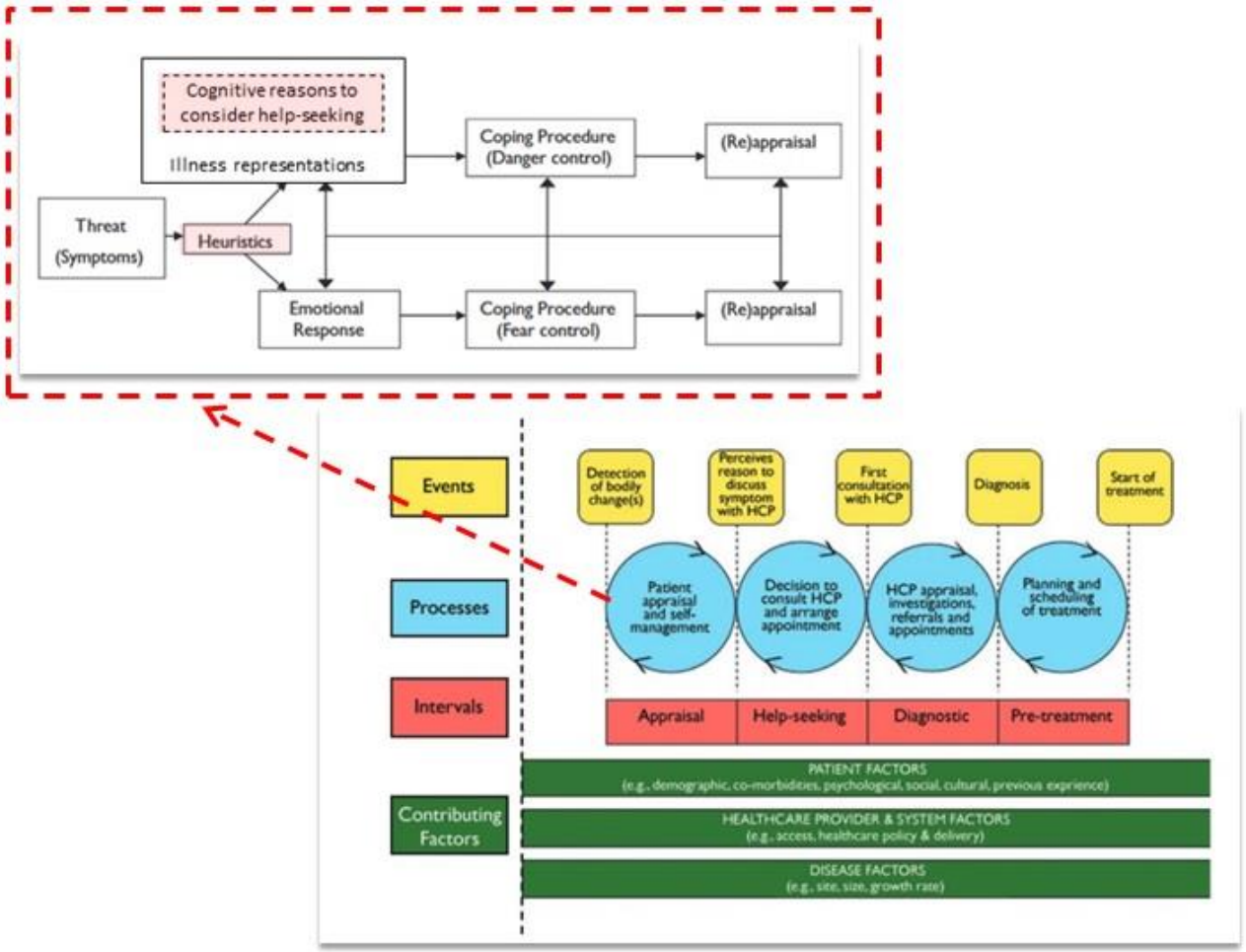

Figure 20 Illustration of how heuristics and 'cognitive reasons to consider help-seeking' fit into the MPT

The first stage of questionnaire development consisted of generating a pool of items relevant to the construct of interest (DeVellis, 2011): heuristics and 'cognitive reasons to consider help-seeking'. Items were generated for the following eight heuristics: *Symmetry rule, Rate of Change rule, Duration rule, Age-Illness rule, Optimistic Bias rule, Pattern rule, Severity rule and Novelty rule*. Furthermore, items were also generated for 'cognitive reasons to consider help-seeking'. No items were generated for the *Prevalence rule* and *Stress-illness rule*, because no support for these rules was found in the qualitative data. Items were initially generated for *Location rule*, *Chronology rule* and *Similarity rule*. However, it was decided that items generated for these rules were to be discarded from the PaTH-Q because these heuristics focused on noticing symptoms rather than interpreting symptoms. For instance, individuals frequently noted that they thought their symptoms were due to an infection, ulcer, old injury or allergy.

Questionnaire items were generated based on the definition(s) for heuristics and 'cognitive reasons to consider help-seeking', as well as verbatim phrases and words found in the qualitative data. Drafting survey items based on these data ensured that the wording and concepts were comprehensible and applicable to the (future) target population (Bryman, 2006). Nevertheless, when choosing the words or phrases from the qualitative data, those that 1) used complex language which may only be understood by individuals with a higher educational background or 2) were related to a specific cancer type were either revised or discarded.

Regarding the first point, this was based on the rationale that when the (future) target populations' educational background is not known the questionnaire should not require reading skills beyond that of a 12-year old (Streiner et al., 2015). To ensure that the PaTH-Q could be understood by as many people as possible, regardless of their educational background, the A-Z of alternative words published by The Plain English campaign (2001) was used as a resource for alternative words or phrases. It is acknowledged that other techniques, such as those based on the number of words in each sentence or the numbers of syllables in each word, or the 'cloze' technique could have been used. Nevertheless, it has been suggested that readability formulas are often unsuitable when applied to questionnaire design, because meaning may be dependent on one key word and each item can be regarded as an independent section (Streiner et al., 2015).

Regarding the second point, this was based on the rationale that the questionnaire would be applicable across cancer types. Furthermore, when the (future) target population would complete the PaTH-Q some HCPs may not have mentioned the possibility of cancer when

they have referred their patient for further tests. Therefore the PaTH-Q was developed very carefully in order to ensure that it does not mention cancer, so as to minimise distress for those still awaiting a diagnosis and because it is understood that the majority of people do not consider cancer when interpreting their symptoms (Molassiotis et al., 2010; Whitaker et al., 2014).

Survey items were not drafted from the items obtained as part of the systematic review (Chapter Two). This was because no relevant items were found from measures that were reliable or valid.

In total, 72 items were generated for PaTH-Q Version One. To date there is no agreement regarding how many items should be generated for a new questionnaire (Preston & Colman, 2000; Streiner et al., 2015). Nevertheless, authors have suggested that it is better to be over inclusive as this will ensure that a questionnaire will demonstrate internal consistency by enhancing the likelihood of items correlating highly between each other (Streiner et al., 2015). Having more questions in the initial item pool also allows for ill-performing items to be excluded whilst ensuring a significant number of remaining items. Nunnally (1978) suggested that the initial item pool should contain 1.5 to two times as many items as the final instrument as this process ensures that there will still be enough adequate items available should items be discarded as part of the development process. Therefore, four items were drafted for each heuristic and for 'cognitive reasons to consider help-seeking' in order to allow for the removal of items which might not correlate with each other.

A multi-item scale was chosen for the PaTH-Q as it would have been impossible to capture the content domain with one overall question. It has also been argued that whilst single-items scales enable the instrument to be evaluated for test-retest reliability, such scales may be less reliable as the internal consistency reliability cannot be established (Loo, 2002). Furthermore, single-item scales are also more prone to random measurement errors. Random measurement errors are less likely to happen in multi-item scales (Hoeppner, Kelly, Urbanoski, & Slaymaker, 2011). It has been suggested that single-item measures should only be considered a viable option when the single item reflects a homogeneous construct (as indicated by Cronbach's alpha > 0.85) or a unidimensional construct as determined by item factor analysis (Loo, 2002).

During the development process it was also decided that the PaTH-Q should consist of two sections: 'Barriers to seeking help' and 'Triggers to seeking help' given that the MPT suggests that both barriers and triggers affect the help-seeking process (Scott et al., 2013). The stem to determine 'Barriers to seeking help' (At first, I thought I did not need to see a healthcare professional because…) was planned to tap into what may have extended the appraisal interval, whereas the stem to determine 'Triggers to seeking help' was planned to tap into what may have shortened the appraisal interval (I thought I needed to see a healthcare professional because…). Furthermore, it was decided that items should be identical to each other in both sections in order to determine whether psychosocial factors influencing symptom appraisal and help-seeking behaviour would be different or the same for both stems.

A Likert scale was chosen as the optimal response format for the questionnaire for numerous reasons. Firstly, Likert scales have been shown to be the most robust measurement scales (Preston & Colman, 2000). Secondly, although authors have not provided a definitive agreement on the number of response categories which will offer the most reliable result, existing research has suggested that reliability and validity are improved by using 5- to 7-point scales rather than those with the fewest response categories (Dawes, 2008). It has also been noted that the positive contribution to reliability, due to more scale points, decreases after 7 points (Krosnick & Presser, 2010). For example, Givon and Shapira (1984, as cited in Krosnick & Presser, 2010) found that reliability increased up to 11 points, but the increases that occurred after 7 points were quite minimal. Further, more recent research on this topic, which compared 5-point (Agree to Disagree) scales with longer scales (specifically 7-point and 11-point scales) in terms of measurement quality revealed that 7- or 11-point scales have lower data quality (Revilla, Saris, & Krosnick, 2013). Based on their study's findings, Revilla et al. (2013) recommended that if researchers want to use Agree to Disagree scales, they should use 5-point scales. Thirdly, a 5-point scale enables participants to have a neutral opinion whereas an even number would force participants to one opinion or another, which could ultimately lead to erroneous measurement (Krosnick & Presser, 2010). As a result of the aforementioned research outcomes, a 5-point scale (which had the following categories: 5 ('Strongly Disagree'), 4 ('Disagree'), 3 ('Neither agree nor disagree'), 2 ('Agree'), 1 ('Strongly Agree') was chosen as the optimal response format for the PaTH-Q.

In summary, Version One of the PaTH-Q was designed to examine the extent to which eight different heuristics (*Rate of Change rule, Age-Illness rule, Pattern rule, Duration rule, Symmetry rule, Optimistic bias rule, Novelty rule, Severity rule*) and 'cognitive reasons to consider help-seeking' influenced the perceived need to seek help. Version One of the PaTH-Q consisted of two sections: 'Barriers to seeking help' and 'Triggers to seeking help'. Each section contained nine subscales (eight heuristics subscales and one 'cognitive reasons to consider help-seeking' subscale). Items were rated on a five-point Likert Scale ranging from "Strongly Disagree" to "Strongly Agree" (see **Appendix 8**).

4.3 Content Validation of Version One

4.3.1 Background

Content validity is defined as the degree to which elements of an instrument are relevant to, and representative of, the targeted construct for a particular assessment purpose (Haynes et al., 1995). As such, item content validity (I-CVI) is the extent to which each item fits the concept, whereas the total (sub)scale level content validity (S-CVI) is defined as the overall representativeness of all items as a measure of construct (Waltz, Strickland, & Lenz, 1984). Determining content validity is a vital element in questionnaire development, because without adequate content validity, reliability of an instrument cannot be established (Beck & Gable, 2001). Furthermore, it has been noted that content validity is a prerequisite for construct and criterion-related validity (Waltz, Strickland, & Lenz, 1984) and should therefore be determined immediately after items have been developed as this enables refinement and/or replacement of items prior to questionnaire preparation and administration (Schriesheim, Powers, Scandura, Gardiner, & Lankau, 1993). Content validity is usually determined via consulting an expert panel to get systematic feedback on questionnaire items. An expert panel tends to be chosen according to their: 1) publication history, national presentations and research on the phenomenon of interest, 2) familiarity with the phenomenon of interest [through clinical practice] and 3) expertise with regard to the conceptual framework being measured (Davis, 1992; Grant & Davis, 1997).

4.3.2 Aim

The aim of this study was to establish the content validity of the PaTH-Q (Version One) in order to:

1. determine which elements of the instrument are relevant to, and representative of, the targeted constructs, namely heuristics and 'cognitive reasons to consider help-seeking';
2. to refine, remove and add items prior to final questionnaire preparation and administration.

4.3.3 Methods

4.3.3.1 Participants

The expert panel was selected based on the experts' experience in early cancer diagnosis research, questionnaire development and theoretical expertise. The invited panel consisted of academic researchers, academic GPs and experts in the field of questionnaire design. To date there is no consensus on the ideal number of experts to be used in expert panel studies pertaining to questionnaire development. For example, Lynn (1986) suggested a minimum of three experts; anything below that (e.g. n = 2) would not be significantly justifiable and could result in flawed findings (e.g. the instrument might be determined to be content invalid when it is actually valid). In terms of the maximum number, this is not set in concrete, but Lynn (1986) noted that it is not likely to exceed ten. Studies that have examined women's help-seeking behaviour and the associated factors influencing self-discovery of a breast symptom, as well as a study on the development of a measurement tool to assess public awareness of cancer used 4 (O'Mahony & Hegarty, 2009), 8 (O'Mahony et al., 2013) and 16 experts (Stubbings et al., 2009) respectively. Authors from these studies did not provide any further explanation as to why this number of experts was chosen to determine content validity. Thus, given the lack of consensus on the ideal number of experts to be used it was decided to aim for between 3 to 10 experts. A study invitation was sent to 17 potential expert reviewers. No ethical approval was required for this study (see **Appendix 9**), although ethics committee principles and informed consent and anonymity of data were followed throughout the study.

4.3.3.2 Materials

Seventeen expert reviewers were sent an email inviting them to participate in the study (see **Appendix 10**). Conditional on their willingness to participate, a review package was sent to each expert reviewer by mail.

The review package included the following material:

1. *Cover letter*. The cover letter outlined why the individual was chosen as an expert reviewer and what their participation would entail. The cover letter also explained why measuring these constructs is of importance (see **Appendix 11**).
2. *Content review questionnaire with rating instructions.* Expert reviewers were provided with instructions at the beginning of the review questionnaire. Additionally, the conceptual definition for heuristics and 'cognitive reasons to consider help-seeking' as well as the different dimensions of the construct were outlined. Each expert was asked to rank the items based on their representativeness and clarity, in addition to being asked whether an item should be deleted.

   Representativeness of each item was ranked on a four-point scale: 1 = item is not representative, 2 = item needs major revisions to be representative, 3 = item needs minor revisions to be representative, 4 = item is representative.

   Item clarity was also rated on a four-point scale: 1 = item is not clear; 2 = item needs major revisions to be clear; 3 = item needs minor revisions to be clear; 4 = item is clear. Grant and Davis (1997) proposed that item clarity should be evaluated at the end of the content review questionnaire. However, Rubio, Berg-Weger, Tebb, Lee, and Rauch (2003) found that asking experts to indicate item clarity at the end of the questionnaire was potentially unclear and therefore recommended that item clarity should be assessed at the same time as item representativeness. This recommendation was taken into account for the content review questionnaire and thus experts were asked to rate item clarity alongside item representativeness.

   Expert reviewers were also asked to indicate whether an item should be deleted. Rubio et al. (2003) suggested specifying the deletion of any item at the end of the questionnaire. However, following their suggestion on item clarity, the question concerning whether items should be deleted was assessed at the same time as item representativeness and clarity.

   Space was also provided for the expert reviewers at the end of each section to comment on the item or to suggest revisions in order to improve any of the items. At the end of the questionnaire they were also asked to rate the comprehensiveness of the entire questionnaire and state whether they thought that there were any constructs that the questionnaire missed (see **Appendix 12**).

Expert reviewers were given one month to complete the package, with a polite reminder being sent after two weeks asking them to complete and return the package if they had not yet done so.

4.3.3.3 Data Analysis

Content validity indices were calculated at the scale and item level, for all of the 36 items in each of the two sections, to ascertain the degree to which the experts believed the items and subscales were representative of the relevant construct. Calculations were also computed for item clarity and item deletion.

The content validity of the questionnaire package was determined by calculating a content validity index (CVI). The CVI was calculated at the item level (I-CVI) and subscale level (S-CVI) average.

I-CVI was calculated to determine the content validity of individual items to determine which item(s) should be revised or deleted from the instrument. I-CVI was determined using the guidelines recommended by Polit, Beck, and Owen (2007) and Rubio et al. (2003). Rubio et al. (2003) noted that the standard method for determining the I-CVI is calculated by counting the number of experts who rated an item as either 3 or 4[25] and then dividing it by the total number of items. See **Figure 21** for an illustration of how the I-CVI was calculated for items for the *Rate of Change rule*, Section One. The same methodology was applied to all of the heuristics and 'cognitive reasons (not) to consider help-seeking' in Section One and Section Two. Items were considered content valid if the I-CVI was 0.78 or higher, as recommended by Polit et al. (2007). As suggested by the authors, items that had an I-CVI of 0.78 or lower were revised or deleted.

Items	**Experts**										**I-CVI**
	Ex[26] 1	**Ex 2**	**Ex 3**	**Ex 4**	**Ex 5**	**Ex 6**	**Ex 7**	**Ex 8**	**Ex 9**	**Ex 10**	
At first, I thought I did not need to see a healthcare professional because…											
My symptoms were getting better	4	4	4	4	4	4	4	4	4	4	10/10 = 1.00
My symptoms were coming and going	2	4	4	4	4	4	3	4	4	4	9/10 = 0.90

[25] Items rated as 3 or 4 were recoded as 1, whereas items rated as 1 or 2 were recoded as 0 (Rubio et al., 2003)

[26] Expert

My symptoms did not change	4	4	4	4	2	4	4	4	4	4	9/10 = 0.90
I was getting more symptoms	2	4	1	4	4	4	4	4	4	2	7/10 = 0.70

Figure 21 Items for Rate of Change rule (Section One) as rated by experts to calculate I-CVI

S-CVI/Average (S-CVI/Ave) was calculated to establish the content validity of the nine subscales to determine the proportion of agreement within the instrument. The following formula was used to calculate S-CVI/Ave (Polit & Beck, 2006):

S-CVI/Ave = [Sum of I-CVIs] ÷ [Number of items in a (sub)scale]

Therefore, for the items for *Rate of Change rule*, Section One, the S/CVI Average was computed as follows: 1.00 + 0.90 + 0.90 + 0.70 / 4 = 0.88. The same methodology was applied to all of the heuristics and 'cognitive reasons (not) to consider help-seeking' in Section One and Section Two.

As recommended by Polit and Beck (2006), in order to determine the S-CVI/Ave for each of the subscales the average was calculated across all items for each of the subscales. Each subscale was deemed to be content valid if the S-CVI/Ave was 0.80, as recommended by (Davis, 1992).

Given that no indices exist regarding item clarity and item deletion, the same procedure as recommended for the calculation of the I-CVI and S-CVI/Ave was used to determine the clarity index (Polit & Beck, 2006). Items were considered to be clear if they had an index above 0.78 whereas each subscale was considered to have a good clarity index if the average score was 0.80, which is consistent with the recommended level of the I-CVI and S-CVI/Ave.

In order to determine the I-CVI, S-CVI/Ave, item and subscale clarity index, and whether items should be deleted questionnaire responses were entered into and analysed in SPSS 22.

Expert reviewers' qualitative responses were read and if there was consensus amongst reviewers that an item should be modified or deleted this was taken into account and amendments and/or additions made where appropriate.

4.3.4 Results

Of the 17 experts who were asked to join the expert panel, 10 (59%) agreed to participate and returned their completed packages.

Details on the item representativeness, item clarity and qualitative responses can be found in **Table 33** to **Table 41.**

4.3.4.1 Item Representativeness

For Section One (Barriers to seeking help) 23 out of 32 heuristics items received an I-CVI of 0.78 or above, whereas for Section Two (Triggers to seeking help) 20 out of 32 heuristics items received an I-CVI of 0.78 or above. All of the items for 'cognitive reasons to consider seeking help' (n = 4) and 'cognitive reasons not to consider seeking help' (n = 4) received an I-CVI of 0.78 or above.

Upon analysis of which items had a low I-CVI it emerged that 21 problematic items were reverse coded (e.g. **Table 33**, *Rate of Change rule*, Section One, Item No. 3 'At first, I thought I did not need to see a healthcare professional, because my symptoms did not change'). For Section One, nine of the 16 reverse heuristics items had an I-CVI below 0.78. For Section Two, 12 of the 16 reverse heuristics items had an I-CVI below 0.78.

Content validity indices were also calculated for each of the subscales in Section One and Section Two. All of the subscales, with the exception of *Optimistic Bias rule* in Section Two (S-CVI/Ave = 0.75) had an S-CVI/Ave of above 0.80.

4.3.4.2 Item Clarity

For Section One (Barriers to seeking help) 28 out of 32 heuristics items received an item clarity index of 0.78 or above, whereas for Section Two (Triggers to seeking help) 26 out of 32 heuristics items received an item clarity index of 0.78 or above. All of the items for 'cognitive reasons to consider seeking help' (n = 4) and 'cognitive reasons not to consider seeking help' (n = 4) received an item clarity index of 0.78 or above.

Upon analysis of which items had a low I-CVI it emerged that all 10 problematic items were reverse coded. For Section One, four of the 16 reverse heuristics items had an item clarity index below 0.78. For Section Two, six of the 16 reverse heuristics items had an item clarity index below 0.78.

Item clarity indices were also calculated for each of the subscales in Section One and Section Two. All of the subscales had an item clarity index of above 0.80.

4.3.4.3 Comprehensiveness of the PaTH-Q

In response to the question 'Do you think the questionnaire represents the entire domain of heuristics?' 8 (80%) experts answered 'yes', one expert answered 'no'. There was one missing response for this question. **Table 42** provides an overview of additional comments provided by experts regarding any constructs the instrument possibly missed.

4.3.4.4 Qualitative Responses

Qualitative feedback from expert reviewers raised three types of issues. Firstly, expert reviewers suggested that some items should be re-worded to make items clearer and easier to understand, for example because they sounded confusing or too similar to each other, or because there appeared to be an overlap between items between different heuristics.

Secondly, a number of reviewers commented on the difficulty of the reverse items and suggested that reverse phrased items should be deleted.

Thirdly, experts suggested that for some heuristics, for example *Pattern rule*, the items did not capture the full spectrum of the definition. As such, new items were generated for *Pattern rule* in order ensure that they would cover the full definition.

Table 33 Rate of Change rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	My symptoms were getting better	1.00	0.88	1.00	0.90	n = 1	**P8:** There is no distinction between severity of each symptom (e.g. severity of pain) and number of symptoms. For example "my symptoms were getting better" could be interpreted as "the severity of one symptom improving " or "the number of symptoms decreased"
2	My symptoms were coming and going	0.90		1.00		n = 1	**P1:** Doesn't this relate to duration? **P7:** The problem here is the periodically of the intermittency. This could be rapid rises/falls – like labour pains, or days may go past with symptoms/no symptoms
3[R]	My symptoms did not change	0.90		1.00		n = 2	**P4:** *(my symptoms)* were not changing **P8:** See comment above (Q1, Section 1)
4[R]	I was getting more symptoms	0.70		0.60		n = 4	**P1:** Phrase does not make logical sense with the first clause **P7:** this could mean more severity/frequency, or additional symptoms. It may be better to give an indication which you need to clarify **P10:** Difficult. Double negative response. Leave in Section 2

[R] = reverse worded question

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
							P11: Feels like a trick question
SECTION 2 - I thought I needed to see a healthcare professional because…							
1[R]	My symptoms were getting better	0.67	0.92	0.78	0.95	n = 1	**P10:** Again - double negative **P11:** This is a bit confusing. I think people might misread the stem
2[R]	My symptoms were coming and going	1.00		1.00		n = 0	**P7:** See comment above (Q2, Section 1)
3	My symptoms did not change	1.00		1.00		n = 0	**P4:** *(my symptoms)* were not changing
4	I was getting more symptoms	1.00		1.00		n = 0	**P7:** See comment above (Q4, Section 1) **P11:** Better to ask about rapid change of one's symptoms rather than symptoms becoming more numerous
Additional Comments/Items:		**P1:** I don't understand why you repeat each item with a different leading clause There is no item relating to suddenness of onset **P2:** Section 1 – bit uncertain how easily understood "coming and going" would be. Presumably you'll pilot so probably fine. Section 2 – "symptoms were getting better" felt a bit jarring because reverse scored **P6:** Some of these might seem like "trick questions"? **P11:** Not sure if these questions adequately cover "rapidly worsening symptom"					

Table 34 Severity rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	My symptoms did not stop me from doing everyday activities	1.00	0.85	1.00	0.92	n = 0	**P1**: These essentially ask the same thing *(expert referring to Q1 and Q2, Section 1)* **P4:** Section 1 –Q1, Q2 – very similar. **P5:** Section 1 –Q1, Q2 – 1 and 2 would appear closely similar. Getting out of bed is a grade of severity and begs the question why don't you ask about other limitations e.g. going to work.
2	I was able to do my normal activities	1.00		1.00		n = 0	
3[R]	I was not able to get out of bed	0.70		0.70		n = 4	**P4:** *(I was not able to get out of bed)* because of my symptoms **P10:** Double negative **P11:** Confusing
4[R]	My symptoms interfered with my daily life	0.70		0.80		n = 3	**P10:** Double negative
SECTION 2 - I thought I needed to see a healthcare professional because…							
1[R]	My symptoms did not stop me from doing everyday activities	0.67	0.84	0.78	0.86	n =3	**P10:** Section 1 only
2[R]	I was able to do my normal activities	0.67		0.78		n =3	**P10:** Section 1 only
3	I was not able to get out of bed	1.00		0.89		n = 1	**P4:** *(I was not able to get out of bed)* because of my symptoms
4	My symptoms interfered with my daily life	1.00		1.00		n = 2	

[R] = reverse worded question

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
Additional Comments/Items:		**P1:** Severity seems to be operationalised in terms of impact on daily activities in a rather vague sense. Could distinguish between basic activities such as walking and eating and instrumental activities like shopping and preparing meals. **P7:** Look at my pattern comments. Those heuristics have become a bit conflated.					

Table 35 Age-Illness rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	People at my age get this symptom	1.00	0.80	1.00	0.85	n = 0	**P2:** Delete 'at' **P11:** Perhaps add in something to indicate that symptoms are "normal" or harmless
2	I thought my symptoms were just due to my age	1.00		1.00		n = 0	
3[R]	People at my age do not get this type of symptom	0.60		0.70		n = 4	**P10:** Again strange **P11:** Double negative confusing
4[R]	I did not expect to get this symptom at my age	0.60		0.70		n = 4	**P10:** Double negative **P11:** Double negative confusing **P8:** It seems repetitive. Too similar to previous items
SECTION 2 - I thought I needed to see a healthcare professional because…							
1[R]	People at my age get this symptom	0.67	0.84	0.67	0.84	n = 4	**P10:** Ok here **P11:** Confusing
2[R]	I thought my symptoms were just due to my age	0.67		0.67		n = 4	**P10:** Ok here **P11:** Confusing
3	People at my age do not get this type of symptom	1.00		1.00		n = 0	
4	I did not expect to get this symptom at my age	1.00		1.00		n = 0	
Additional Comments/Items:		**P1:** You will need to be careful with these items. By referring to "my age" you are likely to find people respond differently due to age. This kind of age heuristic interaction would violate the psychometric assumption of independence of items responses and covariates leading to item bias. More general phrases such as "symptoms are related to normal ageing" may be less problematic **P5:** Double negatives/positives are confusing to participants					

[R] = reverse worded question

Table 36 Novelty rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	I often get these symptoms	1.00	0.88	1.00	0.90	n = 0	
2	My symptoms were similar to symptoms I had in the past	0.90		1.00		n = 0	
3[R]	I had never experienced these symptoms	0.80		0.80		n = 4	**P1:** I had never experienced these symptoms before **P10:** Double negative **P11:** Confusing because double negative
4[R]	My symptoms were unexpected	0.80		0.80		n = 4	**P10:** Double negative **P11:** Confusing because double negative
SECTION 2 - I thought I needed to see a healthcare professional because…							
1[R]	I often get these symptoms	0.89	0.89	0.78	0.89	n = 3	**P10:** Different in this context **P11:** The problem with this is that it could be confused with rate of change heuristic. Not sure what agreeing with this means.
2[R]	My symptoms were similar to symptoms I had in the past	0.67		0.78		n = 4	**P10:** Different in this context
3	I had never experienced these symptoms	1.00		1.00		n = 0	
4	My symptoms were unexpected	1.00		1.00		n = 0	
Additional Comments/Items:		**P11:** Not sure I fully understand the heuristic					

[R] = reverse worded question

Table 37 Pattern rule (Version One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1[R]	I was in a lot of pain	0.67	0.84	0.78	0.89	n = 3	**P10:** Keep in Section 2 **P11:** Strange question
2[R]	My symptoms were alarming	0.78		0.89		n = 3	**P10:** Keep in Section 2 **P11:** Strange question
3	My symptoms were only mild	1.00		1.00		n = 0	**P11:** Why measure the "mild" feature of symptoms what about "diffuse, ambiguous or vague"?
4	My symptoms were difficult to notice	0.90		0.90		n = 1	**P10:** Keep in Section 2 **P11:** Strange question
SECTION 2 - I thought I needed to see a healthcare professional because…							
1	I was in a lot of pain	1.00	0.85	0.89	0.84	n = 1	
2	My symptoms were alarming	1.00		1.00		n = 1	
3[R]	My symptoms were only mild	0.75		0.78		n = 2	
4[R]	My symptoms were difficult to notice	0.63		0.67		n = 3	
Additional Comments/Items:		**P2**: I find the items marked * (Section 1 - Q1, Q2: Section 2 – Q3, Q4) counter intuitive so challenging to assess **P4:** Consider adding something like ' my symptoms could have been caused by a number of different things' **P7:** I worry that three of these reflect severity: only the last examine 'diffuse', 'ambiguous' should you replace one of the top three, and use the 'vague' word? **P11:** Again, not sure I really understand the heuristic. I think you should refine it. I think rethink what the characteristics of symptoms are that fit with the "pattern" heuristic and design questions accordingly.					

[R] = reverse worded question

Table 38 Duration rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	I thought my symptoms were temporary	1.00	0.85	1.00	0.90	n = 0	
2	I thought my symptoms would last a short time	1.00		1.00		n = 0	
3[R]	My symptoms lasted for longer than I expected	0.70		0.80		n = 3	**P10:** Section 2 **P11:** Confusing suggest reword
4[R]	My symptoms were persistent	0.70		0.80		n = 2	**P10:** Ok
SECTION 2 - I thought I needed to see a healthcare professional because…							
1[R]	I thought my symptoms were temporary	0.67	0.84	0.67	0.81	n = 3	**P2:** This seems ambiguous – would people interpret it as "I thought my symptoms were temporary" but they turned out to be persistent so I thought I needed to see a healthcare professional? **P10:** Section 1 **P11:** Confusing
2[R]	I thought my symptoms would last a short time	0.67		0.67		n = 3	**P7:** See comment above (Q1, Section 2) **P10:** Section 1 **P11:** Confusing
3	My symptoms lasted for longer than I expected	1.00		1.00		n = 1	
4	My symptoms were persistent	1.00		0.89		n = 1	**P11:** Suggest reword
Additional Comments/Items:		**P1:** There seems to be considerable overlap with items in the "rate of change" section, e.g. "symptoms were coming and going" **P5:** Temporary/last a short time are two constructs that would be					

[R] = reverse worded question

	different to participants to understand the difference between. **P11:** “Persistence” could be interpreted as worrying or reassuring

Table 39 Symmetry rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1[R]	A friend or family member had similar symptoms which turned out to be signs of illness	0.80	0.84	0.90	0.93	n = 2	**P10:** Leave in Section 2 **P11:** Ambiguous - could mean serious or trivial illness
2[R]	My symptoms were similar to those I saw in a health campaign	0.80		0.90		n = 3	**P10:** Leave in Section 2 **P11:** Was the health campaign reassuring or alarming?
3	I could explain my symptoms	0.90		0.90		n = 0	**P1:** This could be serious or benign
4	I knew what had triggered my symptoms	0.90		1.00		n = 0	**P1:** This could be serious or benign
SECTION 2 - I thought I needed to see a healthcare professional because…							
1	A friend or family member had similar symptoms which turned out to be signs of illness	0.90	0.84	0.89	0.89	n = 2	**P11:** Ambiguous - could mean serious or trivial illness
2	My symptoms were similar to those I saw in a health campaign	0.90		0.89		n = 1	**P11:** Was the health campaign reassuring or alarming?
3[R]	I could explain my symptoms	0.90		0.89		n = 3	**P10:** Ok in this context **P11:** Confusing
4[R]	I knew what had triggered my symptoms	0.90		0.89		n = 3	**P10:** Ok in this context **P11:** Confusing
Additional Comments/Items:		**P11:** Not sure I fully understand the heuristic					

[R] = reverse worded question

Table 40 Optimistic Bias rule (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	I am generally a healthy person	0.90	0.85	0.90	0.90	n = 0	**P11:** Ambiguous
2[R]	I am often ill	0.90		1.00		n = 0	**P11:** Ambiguous
3	Most symptoms are harmless	0.90		0.90		n = 1	**P11:** Confusing. Diseases can be harmless but symptoms don't cause harm in themselves
4[R]	Symptoms rarely get better on their own	0.70		0.80		n = 3	**P11:** Confusing
SECTION 2 - I thought I needed to see a healthcare professional because…							
1[R]	I am generally a healthy person	0.67	0.75	0.75	0.83	n = 3	**P11:** Ambiguous **P2:** Generally healthy… but in this instance I knew something was wrong so I sought help? Not sure how people will interpret
2	I am often ill	0.78		0.89		n = 1	**P11:** Ambiguous
3[R]	Most symptoms are harmless	0.67		0.78		n = 2	
4	Symptoms rarely get better on their own	0.89		0.89		n = 1	
Additional Comments/Items:		**P11**: I think measuring this heuristic needs a rethink					

[R] = reverse worded question

Table 41 Cognitive reasons (not) to consider help-seeking (Round One)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
SECTION 1 - At first, I thought I did not need to see a healthcare professional because…							
1	I thought something was wrong	0.90	0.90	1.00	1.00	n = 0	
2	My symptoms were not normal	0.90		1.00		n = 0	
3	I thought my symptoms were serious	0.90		1.00		n = 0	**P4:** I didn't think my symptoms were serious
4	Something needed to be done about my symptoms	0.90		1.00		n = 0	
SECTION 2 - I thought I needed to see a healthcare professional because…							
1	I thought nothing was wrong	0.90	0.90	1.00	0.98	n = 1	
2	My symptoms were normal	0.90		0.90		n = 1	
3	I thought my symptoms were not serious	0.90		1.00		n = 1	
4	Nothing needed to be done about my symptoms	0.90		1.00		n = 1	
Additional Comments/Items:		**Reasons to consider help-seeking:** **P1:** Is this meant to form a subscale? If so it seems you expect multiple factors Do these items also not relate to heuristics? None of these factors appear to assess emotional factors or coping directly **P8:** The items are only representations of cognitive and emotional factors but not of "perceived ability to cope with symptoms" and "consequences of symptoms" **P11:** I am not sure how these reasons to consider seeking help differ from the reasons discussed in previous questions, and how they fit with items in your model. All written clearly. Not sure they are comprehensive.					

	Reasons not to consider help-seeking: **P1:** I don't see why you ask the same question reversing the polarity? **P11**: Likewise, these may not be comprehensive

Table 42 Additional comments provided by experts regarding any constructs the instrument possibly missed

Are there any constructs you think the instrument missed?
P1: Not specifically but in places you may need to add items to ensure full range of the construct is assessed There is a lot of redundant items. Asking the same thing twice does not increase validity and where the direction makes no sense logically in relation to the anchor clause may reduce validity and potentially reliability too **P2:** I am not sure this fits your purpose but should there be something on acknowledgment of symptoms but too many other competing demands meant help was not sought? Should there be something on fear of an abnormal result? **P4:** This is a general comment applying to all sections – I think people will find it hard to respond if something was happening but wasn't a key barrier or trigger. E.g. if someone was getting more symptoms but this wasn't a reason for not seeking help, they may tick "agree". By having "not" in the instructions you ned up with complex double-negatives for the reversed items. **P6:** I think this covers a significant no of heuristics and the items were clear and made sense. I wondered about emotional influences (e.g. I was frightened) /fatalism and also 'normalising' in a broader sense (beyond age) (+environmental factors) (e.g. stress-illness rule/stereotypes) I also wondered if people will get confused responding to the same item but for 'reasons for' and 'for not' visiting HCP hopefully piloting with patients will help ascertain this. **P8:** Two issues to consider throughout the questionnaire: Will you be able to distinguish between patients who did not experience a symptom/situation (e.g. pain) and those who experienced I but did not consider it an important reason for seeking/not seeking help? Maybe there should be a response option "not applicable/never experienced" The reverse coded items, particularly when evaluating reasons for not seeking help introduce multiple negation making it quite confusing for the respondent **P10:** No constructs missed This is a well-constructed questionnaire which shows great evidence of careful conceptual development. It is quite a challenging area to develop. My only thoughts are about the difficulty of some elements where the rater has to make almost a double negative judgment. **P11**: Fear Other priorities

4.3.5 Amendments to Version One

PaTH-Q Version One was amended following this analysis.

Modifications were made on numerous grounds. Firstly, calculations indicated that I-CVIs and item clarity indices were below the recommended guidelines for various items. This was especially the case for reverse items. As such, all reverse items were deleted or rephrased. Secondly, amendments were made in line with qualitative comments where appropriate, especially when the I-CVI and item clarity indices were low. **Table 43** and **Table 44** illustrate the changes that were made to Version One and offer an explanation for the amendment or retainment of items. Version Two of the PaTH-Q can be found in **Appendix 13**.

Table 43 Changes made to items in Section One (Barriers to seeking help) in PaTH-Q

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
RATE OF CHANGE RULE							
1	My symptoms were getting better	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	My symptoms were getting better
2	My symptoms were coming and going			✓		*I-CVI and item clarity index above recommended level of 0.78, but item was deleted as qualitative comments suggested that the item was more representative to Duration rule*	
3[R]	My symptoms did not change		✓			*I-CVI and item clarity index above recommended level of 0.78, 20% suggested deletion of item. The item was amended as reverse items were either deleted or edited as a rule*	My symptoms changed slowly or not at all
4[R]	I was getting more symptoms		✓			*Low I-CVI (0.70), item clarity index (0.60) and 40% suggested deletion of item. Item was amended as reverse items*	I did not get more symptoms

[R] = reverse worded question

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						were either deleted or edited as a rule	
					✓	*Added new item as qualitative feedback suggested that current items do not cover the full spectrum of the definition*	My symptoms started slowly
SEVERITY RULE							
1	My symptoms did not stop me from doing everyday activities		✓			*I-CVI and item clarity index above recommended level of 0.78, but item was amended as the original item contained a double negative statement*	I could still do my everyday activities
2	I was able to do my normal activities			✓		*I-CVI and item clarity index above recommended level of 0.78. However, qualitative responses highlighted that this item was too similar to Q1 in Severity rule and thus it was decided that either Q1 or Q2 should be deleted.*	
3^{R}	I was not able to get out of bed		✓			*Item amended as I-CVI below recommend level (0.70) and 40% suggested deletion of item.*	I was still able to get out of bed

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						Item was also amended as reverse items were either deleted or edited as a rule	
4[R]	My symptoms interfered with my daily life			✓		*Item deleted as I-CVI below recommend level (0.70) and 30% suggested deletion of item. Item was also deleted as reverse items were either deleted or edited as a rule*	
					✓	*Added new item as qualitative feedback suggested adding items on basic and instrumental activities. In qualitative data individuals with colorectal, pancreatic and oral symptoms noted that they had to adjust their eating habits as symptoms progressed*	I was still able to eat
					✓	*Added new item as qualitative feedback suggested adding items on basic and instrumental activities*	I was still able to move
AGE-ILLNESS RULE							
1	People at my age get			✓		*I-CVI and item clarity index*	

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	this type of symptom					*above recommended level of 0.78. However, qualitative responses highlighted that general phrases may be less problematic*	
2	I thought my symptoms were just due to age rather than illness		✓			*I-CVI and item clarity index above recommended level of 0.78. However, item was amended to become more grammatically coherent*	I thought my symptoms were due to age rather than illness
3[R]	People at my age do not get this type of symptom		✓			*Item amended as I-CVI (0.60) and item clarity index (0.70) below recommend level and 40% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	People at my age do get this type of symptom
4[R]	I did not expect to get this symptom at my age		✓			*Item amended as I-CVI (0.60) and item clarity index (0.70) below recommend level and 40% suggested deletion of item. Item was also amended as reverse items*	I expected to get this type of symptom at my age

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						were either deleted or edited as a rule.	
					✓	*Added new item as qualitative feedback suggested that general phrases may be less problematic*	It is normal for someone like me to get this symptom
NOVELTY RULE							
1	I often get these symptoms	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I often get these symptoms
2	My symptoms were similar to symptoms I had in the past	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	My symptoms were similar to symptoms I had in the past
3^{R}	I never experienced these symptoms			✓		*I-CVI and item clarity index above recommended level of 0.78 and 40% suggested deletion of item. The item was deleted as reverse items were either deleted or edited as a rule*	
4^{R}	My symptoms were unexpected		✓			*I-CVI and item clarity index above recommended level of 0.78, 40% suggested deletion of item. However, the item was*	I expected to have these symptoms

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						amended as reverse items were either deleted or edited as a rule	
					✓	*Added new item, as 'I never experienced these symptoms' was deleted*	My symptoms are common
PATTERN RULE							
1^R	I was in a lot of pain		✓			*Item amended as I- CVI (0.67) below recommended level and 30% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	I was in no pain
2^R	My symptoms were alarming			✓		*I-CVI and item clarity index above recommended level of 0.78, 30% suggested deletion of item. However, the item was deleted as reverse items were either deleted or edited as a rule*	
3	My symptoms were only mild	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	My symptoms were only mild
4	My symptoms were	✓				*Item was not amended as I-CVI and item clarity*	My symptoms were

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	difficult to notice					*index above recommended level of 0.78*	difficult to notice
					✓	*Added new item as qualitative feedback suggested that current items do not cover the full spectrum of the definition*	My symptoms were vague
DURATION RULE							
1	I thought my symptoms were temporary	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I thought my symptoms were temporary
2	I thought my symptoms would last a short time		✓			*Item was amended in order for it to match better with the definition even though I-CVI and item clarity index above recommended level of 0.78*	I thought my symptoms would be short lived
3[R]	My symptoms lasted for longer than I expected			✓		*Item deleted as I- CVI (0.70) below recommended level and 20% suggested deletion of item. Item was also deleted as reverse items were either deleted or edited as a rule*	
4[R]	My symptoms were persistent			✓		*Item deleted as I-CVI (0.70) below recommended level and 20% suggested deletion of item.*	

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						Item was also deleted as reverse items were either deleted or edited as a rule	
					✓	*Added new item as qualitative feedback suggested that existing items sounded confusing*	I thought my symptoms would come and go
					✓	*Added new item as qualitative feedback suggested that existing items sounded confusing*	I thought my symptoms would get better on their own
SYMMETRY RULE							
1[R]	A friend or family member had similar symptoms which turned out to be signs of illness		✓			*I-CVI and item clarity index above recommended level of 0.78. However, the item was amended as reverse items were either deleted or edited as a rule*	A friend or family member had similar symptoms which were not signs of illness
2[R]	My symptoms were similar to those I saw in a health campaign		✓			*I-CVI and item clarity index above recommended level of 0.78. However, the item was amended as reverse items were either deleted or edited as a rule*	My symptoms were different to those I saw in a health campaign
3	I could		✓			*Although I-CVI*	I

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	explain my symptoms					*and item clarity index above recommended level of 0.78, item was amended as a qualitative response suggested that it was not clear whether the original item relates to a serious or benign condition. Another qualitative response noted that the corresponding original item sounded confusing in Section Two (Triggers to help-seeking)*	understood my symptoms
4	I knew what had triggered my symptoms	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I knew what had triggered my symptoms
OPTIMISTIC BIAS							
1	I am generally a healthy person	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I am generally a healthy person
2[R]	I am often ill		✓			*I-CVI and item clarity index above recommended level of 0.78. However, item was amended as*	I am rarely ill

Barriers to seeking help							
At first, I thought I did not need to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						reverse items were either deleted or edited as a rule	
3	Most symptoms are harmless	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	Most symptoms are harmless
4[R]	Symptoms rarely get better on their own		✓			*Item amended as I-CVI (0.70) below recommend level and 30% suggested deletion of item*	Symptoms often get better on their own
REASONS TO CONSIDER HELP-SEEKING							
1	I thought nothing was wrong	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I thought nothing was wrong
2	My symptoms were normal	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	My symptoms were normal
3	I thought my symptoms were not serious	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I thought my symptoms were not serious
4	Nothing needed to be done about my symptoms	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	Nothing needed to be done about my symptoms

Table 44 Changes made to items in Section Two (Triggers to seeking help) in PaTH-Q

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
RATE OF CHANGE RULE							
1[R]	My symptoms were getting better		✓			*Item amended as I-CVI (0.67) below recommend level. Item was also amended as reverse items were either deleted or edited as a rule*	My symptoms were getting worse
2[R]	My symptoms were coming and going			✓		*I-CVI and item clarity index above recommended level of 0.78, but item was deleted as qualitative comment in Section One suggested that the item was more representative to Duration rule*	
3	My symptoms did not change		✓			*I-CVI and item clarity index above recommended level of 0.78, but the item was amended as reverse items were either deleted or edited as a rule*	My symptoms changed quickly
4	I was getting more symptoms		✓			*Item was amended to make it more grammatically coherent even though I-CVI and*	I got more symptoms

[R] = reverse worded question

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						item clarity index above recommended level of 0.78	
					✓	*New item was added as the qualitative feedback suggested that current items do not cover the full spectrum of the definition*	My symptoms started suddenly
SEVERITY RULE							
1[R]	My symptoms did not stop me from doing everyday activities		✓			*Item amended as I-CVI (0.67) below recommend level and 30% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	I could not do my everyday activities
2[R]	I was able to do my normal activities			✓		*Item deleted as I-CVI (0.67) below recommend level and 30% suggested deletion of item. Item was also deleted as reverse items were either deleted or edited as a rule*	
3	I was not able to get out of bed		✓			*Although CVI and item clarity index above recommended level of 0.78, item amended to make it more coherent with*	I was unable to get out of bed

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						corresponding item [Q3] in Section One	
4	My symptoms interfered with my daily life			✓		*Although I-CVI and item clarity index above recommended level of 0.78, item deleted as corresponding item in Section One was deleted due to low I-CVI (0.70) and 30% suggested deletion of item*	
					✓	*Added new item as qualitative feedback suggested adding items on basic and instrumental activities. In qualitative data individuals with colorectal, pancreatic and oral symptoms noted that they had to adjust their eating habits as symptoms progressed*	I was unable to eat
					✓	*Added new item as qualitative feedback suggested adding items on basic and instrumental activities.*	I was unable to move
AGE-ILLNESS RULE							
1^{R}	People at my age get this symptom			✓		*Item deleted as I-CVI (0.67) and item clarity index (0.67) were below*	

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						the recommended level and 40% suggested deletion of item. Item was also deleted as reverse items were either deleted or edited as a rule	
2[R]	I thought my symptoms were just due age rather than illness		✓			*Item amended as I-CVI (0.67) and item clarity index (0.67) were below the recommended level, and 40% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	I thought my symptoms were due to illness rather than age
3	People at my age do not get this type of symptom	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	People at my age do not get this type of symptom
4	I did not expect to get this symptom at my age	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I did not expect to get this symptom at my age
					✓	*Added new item as qualitative feedback suggested that general phrases may be less problematic*	It is not normal for someone like me to get this symptom
NOVELTY RULE							
1[R]	I often get these		✓			*Item amended although I-CVI*	I rarely get these

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	symptoms					*and item clarity index above recommended level of 0.78, but 30% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	symptoms
2[R]	My symptoms were similar to symptoms I had in the past		✓			*Item amended as I-CVI (0.67) below recommend level and 40% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	My symptoms were different to symptoms I have had in the past
3	I never experienced these symptoms			✓		*Although I-CVI and item clarity index above recommended level of 0.78, item deleted as corresponding item in Section One was deleted because reverse items were either deleted or edited as a rule*	
4	My symptoms were unexpected		✓			*Although I-CVI and item clarity index above recommended level of 0.78, item was amended to make the wording of item more*	I did not expect to have these symptoms

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						identical to corresponding item [Q4] in Section One	
					✓	*New item generated as Q3 in this section was deleted (justification for deletion outlined above)*	My symptoms were unusual
PATTERN RULE							
1	I was in a lot of pain		✓			*Although I-CVI and item clarity index above recommended level of 0.78, item was amended to make the wording of item more identical to corresponding item in Section One*	I was in pain
2	My symptoms were alarming			✓		*Although I-CVI and item clarity index above recommended level of 0.78, item deleted as corresponding item in Section One was deleted because reverse items were either deleted or edited as a rule*	
3^{R}	My symptoms were only mild		✓			*Item amended as I-CVI (0.75) below recommend level and 20% suggested deletion of item. Item was also amended as*	My symptoms were not mild

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
						reverse items were either deleted or edited as a rule	
4[R]	My symptoms were difficult to notice		✓			*Item amended as I-CVI (0.63) and item clarity index (0.67) below recommend level, and 30% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	My symptoms were easy to notice
					✓	*Added new item as qualitative feedback suggested that current items do not cover the full spectrum of the definition*	My symptoms were striking
DURATION RULE							
1[R]	I thought my symptoms were temporary		✓			*Item amended as I-CVI (0.67) and item clarity index (0.67) below recommend level, and 30% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	I thought my symptoms were not getting better on their own
2[R]	I thought my symptoms would last a		✓			*Item amended as I-CVI (0.63) and item clarity index (0.67) below*	I thought my symptoms would last

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	short time					*recommend level, and 30% suggested deletion of item. Item was also amended as reverse items were either deleted or edited as a rule*	a long time
3	My symptoms lasted for longer than I expected			✓		*Although I-CVI and item clarity index above recommended level of 0.78, original item deleted as it would sound too similar to Q2 ["I thought my symptoms would last a long time"] in this section*	I thought my symptoms should have been gone by then
4	My symptoms were persistent	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I thought my symptoms were persistent
SYMMETRY							
1	A friend or family member had similar symptoms which turned out to be signs of illness	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	A friend or family member had similar symptoms which turned out to be signs of illness
2	My symptoms were similar to those I saw in a health	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	My symptoms were similar to those I saw in a health

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	campaign						campaign
3[R]	I could explain my symptoms		✓			*I-CVI and item clarity index above recommended level of 0.78, 30% suggested deletion of item. However, the item was amended as reverse items were either deleted or edited as a rule*	I could not understand my symptoms
4[R]	I knew what had triggered my symptoms		✓			*I-CVI and item clarity index above recommended level of 0.78, 30% suggested deletion of item. However, the item was amended as reverse items were either deleted or edited as a rule*	I did not know what had triggered my symptoms
OPTIMISTIC BIAS RULE							
1[R]	I am generally a healthy person		✓			*Item amended as I-CVI (0.67) and item clarity index (0.75) below recommend level, and 30% suggested deletion of item.*	My general health is not good
2	I am often ill	✓				*Item was not amended as I-CVI and item clarity index above recommended level of .78*	I am often ill
3[R]	Most symptoms are		✓			*Item amended as I-CVI (0.67) below recommend level*	Most symptoms are a sign

Triggers to seeking help							
I thought I needed to see a healthcare professional because…							
Q	**Original Items**	**No change needed**	**Amended**	**Deleted**	**New Item**	**Explanation**	**Final Items**
	harmless					*and 20% suggested deletion of item*	of illness
4	Symptoms rarely get better on their own	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	Symptoms rarely get better on their own
REASONS TO CONSIDER HELP-SEEKING							
1	I thought something was wrong	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	I thought something was wrong
2	My symptoms were not normal	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0 .78*	My symptoms were not normal
3	I thought my symptoms were serious	✓				*Item was not amended as I-CVI and item clarity index above recommended level of0 .78*	I thought my symptoms were serious
4	Something needed to be done about my symptoms	✓				*Item was not amended as I-CVI and item clarity index above recommended level of 0.78*	Something needed to be done about my symptoms

4.4 Face Validation of Version Two and Version Three

4.4.1 Background

The next stage of the development of the PaTH-Q involved face validation. Nunnally and Bernstein (1994) described face validity as the extent to which a measure reflects what it intends to measure. More specifically, Allen and Yen (1979), Anastasi and Urbina (1997), and Nevo (1985) defined face validity as the degree to which respondents decide whether questionnaire items reflect the targeted construct and assessment objectives from a respondent's perspective. Cognitive interviews are increasingly being used to determine the face validity of questionnaires to gain a further understanding of how respondents perceive and interpret questions, and therefore identify any potential problems that participants may encounter whilst completing the questionnaire (Drennan, 2003). Two techniques used in cognitive interviewing are: 1) verbal probing and 2) 'think aloud' interviewing. Verbal probing involves asking specific questions or probes designed to elicit how the participant has decided to answer a particular question. 'Think aloud' interviewing, on the other hand, requires the participant to 'think aloud' whilst s/he answers a question or the questionnaire. This process enables participants to verbalise any thoughts, feelings, ideas and interpretations as they undertake the task (Collins, 2003). To date, 'think aloud' interviewing has been used in numerous studies to examine how people decide on responding to an item on a questionnaire (French, Cooke, McLean, Williams, & Sutton, 2007; French & Hevey, 2008; Gardner & Tang, 2014; McCorry, Scullion, McMurray, Houghton, & Dempster, 2013; van Oort, Schroder, & French, 2011). It was decided that 'think aloud' interviewing would be most useful to the development of the PaTH-Q as it would provide information about the relevance, usability and applicability of the PaTH-Q. For example, if individuals scored the questionnaire without having fully understood what is being asked of them, this could have an adverse effect on its trustworthiness.

4.4.2 Aim

The aim of this study was to establish the face validity of the PaTH-Q (Version Two) to:

1. determine which elements of the instrument are relevant to and representative of the targeted construct, namely heuristics and 'cognitive reasons to consider help-seeking';
2. to determine the wording, comprehensiveness and usability to ensure that the PaTH-Q would be interpreted as intended.

4.4.3 Methods

4.4.3.1 Participants

Participants were recruited from three Patient Participant Involvement (PPI) networks: 1) South East London Cancer Research Network (SELCRN) PPI Group, 2) Prostate Cancer Support Group at Guy's and St Thomas' Hospital and, 3) Research Design Service (RDS) London. The reason why individuals' who had been diagnosed with cancer (currently or in the past) were also included in the study was because they were most representative of the target population.

Members of these groups were sent information about the study via email by the relevant group co-ordinator (see **Appendix 14** for an example of the approach letter). Interested participants were asked to email the researcher. Prior to taking part in the 'think aloud' interviews, potential participants were sent an information sheet [(see **Appendix 15** for the information sheet used for the face validation of Version Two) (see **Appendix 16** for the information sheet used for the face validation of Version Three)] and asked to confirm they met the study inclusion criteria by answering three screening questions using an online questionnaire [(see **Appendix 17** for the eligibility questions for the face validation of Version Two) (see **Appendix 18** for the eligibility questions for the face validation of Version Three)]. Patients were eligible to take part if 1) they were over 18 years of age; 2) have had a cancer diagnosis (currently or in the past) or went to see a HCP (e.g. doctor or nurse) about their symptoms in the last 6 months; 3) noticed the symptom(s) themselves, and 4) were fluent in speaking English. No ethical approval was required for this study (see **Appendix 9**), although ethics committee principles and informed consent and anonymity of data were followed throughout the study.

4.4.3.2 Procedure

Before commencing with the 'think aloud' task each participant was given the information sheet, which had previously been emailed to them, again. If participants had no queries, the researcher read the following instructions, which were adapted from Darker and French (2009) and French et al. (2007):

> *We have developed a questionnaire to help us understand how people make the decision to visit a doctor about symptoms that might be due to cancer.*

Before we use the questionnaire, we want to check how people understand the questions and whether or not they make sense. In order to do this, I am going to ask you to 'think aloud' as you complete the questionnaire. What I mean by 'think aloud' is that I want you to tell me EVERYTHING you are thinking as you read the instructions, each question and decide how to answer it. I would like you to talk aloud constantly. I do not want you to plan out what you say or try to explain to me what you are saying. Just act as if you are alone in the room speaking to yourself. If you are silent for any long period of time, I will ask you to talk. Please try to speak as clearly as possible, as I shall be recording you as you speak.

Participants were further familiarised with the 'think aloud' method via a warm-up task. During this participants were asked to complete five questions from the 'cause' subscale of the IPQ (Weinman et al., 1996). Specifically they were asked if they considered the cause of their illness to be due to 'My own behaviour', 'Chance or bad luck', 'A Germ or virus', 'Diet or eating habits' or 'Overwork'. This questionnaire was chosen as it uses a 5 point Likert scale similar to that used by the PaTH-Q. The purpose of the warm-up task was to clarify any misunderstandings and difficulties prior to the actual 'think aloud' interview.

Prior to commencing with the actual 'think aloud' task participants were asked if they had any further questions about the task. Once participants began the task they were not interrupted unless they fell silent for 10 seconds, at which point the researcher prompted them to 'keep talking'. Whilst participants completed the questionnaire the researcher sat out of sight from participants in order to minimise any influence. This methodology is similar to previous 'think aloud' protocols (Darker & French, 2009; Ericsson & Simon, 1993; Gilhooly & Green, 1996).

4.4.4 Analysis

Interviews were transcribed verbatim and segmented into text relating to each question. A coding scheme that has previously been used in 'think aloud' studies (Darker & French, 2009) was used to code verbal difficulties expressed by respondents.

1. *No problems* - there were no problems experienced with this item by the participant
2. *Not applicable* - participants expressed the opinion that the item was not appropriate to their circumstances

3. *Incongruent response* - where written and verbal responses were clearly incongruent
4. *Different question* - participants answered a different question to that which was asked
5. *Confusion* - participants indicated that they did not fully understand the content of the item
6. *Missing* - the item was omitted completely
7. *Repeated question* - participants repeated or stumbled over the question several times as a result of difficulty in understanding the item as a result of its structure

All of the transcripts were read and coded by the researcher. Three transcripts (37.5 %) were independently coded by one of the researcher's supervisors (SS). Any disagreements over coding were identified and discussed until agreement was reached.

4.4.5 Results (Version Two of PaTH-Q)

Eight 'think aloud' interviews were conducted in total. Two participants were recruited from the SELCRN PPI group, three participants were recruited from the Prostate Cancer Support Group at Guy's and St Thomas' Hospital and three participants were recruited via RDS London.

4.4.5.1 Preliminary Results – Version Two of PaTH-Q

After four interviews it became clear that there were problems with Version Two.

One participant completely omitted Section One, noting that this section was not appropriate to their circumstances because they made an appointment to see their GP on the same day after noticing their symptoms.

> ***P5:*** *"When did you notice your symptoms? Please indicate the extent to which [...] made you wait. Ah I didn't wait."*
> ***Interviewer: "Okay."***
> ***P5:*** *"Erm …"*
> ***Interviewer: "Did you go immediately?"***
> ***P5:*** *"I had the symptoms at 10 in the morning and I have seen the GP at 11."*
> ***Interviewer: "Okay you had the symptoms in the morning and then you …"***

P5: *"Yes I knew exactly what it was."*

Interviewer: "Okay, okay. Erm … so if you knew exactly, you can't identify with any of these questions can you?"

P5: *"No."*

Following this occurrence and after a consensus meeting with the researcher's supervisors it was decided that Section One and Section Two should be merged as it was acknowledged that individuals might not be able to identify themselves with a stem that asks them to answer items in relation to "At first, I did not see a Healthcare Professional because…". Rather, some individuals may seek help almost immediately after noticing symptoms and as such the stem is not perceived as personally relevant.

Following the merging of both sections the stem was changed to "At the start…". It was also ensured that items under the new stem would try and contain an equal number of barriers and triggers items in order to examine the extent to which heuristics and reasons to consider help-seeking would influence symptom interpretation and TTP.

In addition to these changes the wording was modified for some items (see **Table 45** and **Table 46**) in order to make the items clearer and to fit better with the new stem.

Table 45 and **Table 46** illustrate the changes that were made to Version Two in order to create Version Three (see **Appendix 19**). Following this substantial change, Version Three was used for the remaining 'think aloud' interviews (n = 4). The results of the analysis of the 'think aloud' interviews for those completing Version Two and are presented separately to the results of the analysis of the 'think aloud' interviews for those completing Version Three.

Table 45 Changes made to Barriers items in Version Two following preliminary results of Face Validation

Barriers to seeking help				
Items (Version Two)	**No change made**	**Amended**	**Deleted**	**Revised Items (Version Three)**
At first, I did not see a Healthcare Professional because…				**At the start, …**
RATE OF CHANGE RULE				
My symptoms were getting better		✓		My symptoms seemed to get better
My symptoms changed slowly or not at all	✓			My symptoms changed slowly or not at all
I did not get more symptoms			✓	
My symptoms started slowly			✓	
SEVERITY RULE				
I could still do my everyday activities	✓			I could still do my everyday activities
I was still able to get out of bed	✓			I was still able to get out of bed
I was still able to eat			✓	
I was still able to move			✓	
AGE-ILLNESS RULE				
People at my age do get this type of symptom			✓	
I thought my symptoms were due to age rather than illness	✓			I thought my symptoms were just due to age rather than illness
It is normal for someone like me to get this symptom		✓		I thought it is normal for someone like me to get this symptom
I expected to get this type of symptom at my age			✓	
NOVELTY RULE				
I often get these symptoms			✓	
My symptoms were similar to symptoms I had in the past	✓			My symptoms were similar to symptoms I had in the past
I expected to have these symptoms			✓	
My symptoms are common		✓		I thought my symptoms were common
PATTERN RULE				
I was in no pain			✓	
My symptoms were only	✓			My symptoms were only

Barriers to seeking help				
Items (Version Two)	**No change made**	**Amended**	**Deleted**	**Revised Items (Version Three)**
At first, I did not see a Healthcare Professional because…				**At the start, …**
mild				mild
My symptoms were difficult to notice			✓	
My symptoms were vague	✓			My symptoms were vague
DURATION RULE				
I thought my symptoms would get better on their own	✓			I thought my symptoms would get better on their own
I thought my symptoms would be short lived	✓			I thought my symptoms would be short lived
I thought my symptoms would come and go	✓			I thought my symptoms would come and go
I thought my symptoms were temporary			✓	
SYMMETRY RULE				
A friend or family member had similar symptoms which were not signs of illness			✓	
My symptoms were different to those I saw in a health campaign	✓			My symptoms were different to those I saw in a health campaign
I understood my symptoms	✓			I understood my symptoms
I knew what had triggered my symptoms			✓	
OPTIMSTIC BIAS RULE				
I am generally a healthy person		✓		It was unlikely to be a sign of illness, because I am generally a healthy person
I am rarely ill			✓	
Most symptoms are harmless		✓		I thought most symptoms are harmless
Symptoms often get better on their own			✓	
COGNITIVE REASONS NOT TO CONSIDER HELP-SEEKING				
I thought nothing was wrong	✓			I thought nothing was wrong
My symptoms were normal	✓			My symptoms were normal
I thought my symptoms were not serious			✓	
Nothing needed to be			✓	

Barriers to seeking help				
Items (Version Two)	**No change made**	**Amended**	**Deleted**	**Revised Items (Version Three)**
At first, I did not see a Healthcare Professional because…				**At the start, …**
done about my symptoms				

Table 46 Changes made to Triggers to seeking help items in Version Two following preliminary results of Face Validation

Triggers to seeking help				
Items (Version Two)	**No change made**	**Amended**	**Deleted**	**Revised Items (Version Three)**
At first, I did not see a Healthcare Professional because…				**At the start, …**
RATE OF CHANGE RULE				
My symptoms were getting worse	✓			My symptoms were getting worse
My symptoms changed quickly	✓			My symptoms changed quickly
I got more symptoms		✓		I got more and more symptoms
My symptoms started suddenly	✓			My symptoms started suddenly
SEVERITY RULE				
I could not do my everyday activities			✓	
I was unable to get out of bed			✓	
I was unable to eat	✓			I was unable to eat
I was unable to move	✓			I was unable to move
AGE-ILLNESS RULE				
People at my age do not get this type of symptom		✓		I thought people at my age do not get this type of symptom
I thought my symptoms were due to illness rather than age			✓	
It is not normal for someone like me to get this symptom			✓	
I did not expect to get this symptom at my age	✓			I did not expect to get this symptom at my age
NOVELTY RULE				
I rarely get these symptoms			✓	
My symptoms were different to symptoms I have had in the past			✓	
I did not expect to have these symptoms	✓			I did not expect to have these symptoms
My symptoms were unusual		✓		My symptoms seemed unusual
PATTERN RULE				
I was in pain	✓			I was in pain
My symptoms were not			✓	

Triggers to seeking help				
Items (Version Two)	**No change made**	**Amended**	**Deleted**	**Revised Items (Version Three)**
At first, I did not see a Healthcare Professional because…				**At the start, …**
mild				
My symptoms were easy to notice	✓			My symptoms were easy to notice
My symptoms were striking	✓			My symptoms were striking
				My symptoms were really severe [N.B. This item was added following preliminary results of face validation to ensure that the subscale for *Pattern rule* covers the full range of definition following deletion of items]
DURATION RULE				
I thought my symptoms were not getting better on their own			✓	
I thought my symptoms would last a long time		✓		My symptoms lasted longer than I expected
I thought my symptom should have been gone by then			✓	
I thought my symptoms were persistent		✓		My symptoms were persistent
SYMMETRY RULE				
A friend or family member had similar symptoms which turned out to be signs of illness	✓			A friend or family member had similar symptoms which turned out to be signs of illness
My symptoms were similar to those I saw in a health campaign			✓	
I could not understand my symptoms			✓	
I did not know what had triggered my symptoms	✓			I did not know what had triggered my symptoms
OPTIMSTIC BIAS				
My general health is not good			✓	
I am often ill		✓		I thought it could be a sign of illness, because I am often ill

Triggers to seeking help				
Items (Version Two)	**No change made**	**Amended**	**Deleted**	**Revised Items (Version Three)**
At first, I did not see a Healthcare Professional because…				**At the start, …**
Most symptoms are a sign of illness		✓		I thought most symptoms are a sign of illness
Symptoms rarely get better on their own			✓	
COGNITIVE REASONS TO CONSIDER HELP-SEEKING				
I thought something was wrong			✓	
My symptoms were not normal			✓	
I thought my symptoms were serious	✓			I thought my symptoms were serious
Something needed to be done about my symptoms		✓		I thought something needed to be done about my symptoms

4.4.5.2 Results – Version Two of PaTH-Q

The problems identified by each participant per section for each item can be found in **Appendix 20**.

Table 47 outlines the total number of each type of problem that arose for the four respondents upon completing the PaTH-Q (Version Two).

There were 220 instances (76.39%) (out of 288) in which participants had no problems with the items. This large number was also mainly due to the number of missing responses (n = 36) to Section One of the questionnaire. Further details regarding the types of problems experienced by participants are presented below.

4.4.5.2.1 Not Applicable

Two items were regarded as non-applicable (by three participants).

For instance, one participant noted that she did not give much thought about the duration of her symptoms.

> *"I thought my symptoms were short-lived, probably didn't think one way or the other there, I just accepted they were there and I*

really perhaps ought to think a bit more about it. But didn't, for other reasons. I ought to possibly think more." (Question 26 – P2)

4.4.5.2.2 Incongruent Response

Two participants failed to verbalise their answers to seven questions during the 'think aloud' task and only provided their answers on the paper questionnaire.

4.4.5.2.3 Different Question

Two participants answered a different question to the one being asked. For example, one participant described his symptoms rather than outlining why he sought help.

"*Symptoms often got better on their own. No they were persistent. Erm, disagree."* (Question 7 - P4)

"My symptoms are a sign of illness, well if you think ageing is an illness I suppose it might be. Err, agree, I wouldn't have gone to see them if I didn't think there was something wrong." (Question 32 - P4)

4.4.5.2.4 Confusion

For Section One, two participants noted that they did not fully understand the content of the item.

"My symptoms are common. Don't know about that." (Question 21 - P3)

"*I understood my symptoms. Well I can understand the cause. Erm, don't know how to answer that. I understood my symptoms. I knew what the symptoms were but I didn't know what the meaning was. Erm, neither agree or disagree I think."* (Question 28 - P4)

4.4.5.2.5 Missing

For Section One, one participant (Participant 5) completely omitted all of the questions noting that they were not appropriate to his circumstances, because they noticed their symptoms in the morning and made an appointment to see their GP an hour later following symptom occurrence.

In Section Two, Participant 5 omitted two questions (Question 4 and Question 6), while one question (Question 24) was not answered by Participant 2. No reasons were given for these omissions.

4.4.5.2.6 Repeated Question

Four participants repeated or stumbled over the question several times as a result of difficulty in understanding the item as a result of its structure. This was particularly the case for Question 24 and Question 26 (Section Two). For example:

> *"I thought my symptoms should have been gone by then. No, disagree, no. I thought they were probably age related. So ... I thought my symptoms should have been gone by then. Disagree."* (Question 24 – P4)

4.4.5.3 Results – Version Three of PaTH-Q

The problems identified by each participant per section for each item can be found in **Appendix 21**.

Table 47 outlines the total number of problems that arose for the four respondents. In the examples that follow, the type of problems identified will be outlined further.

There were 151 instances (out of 163) in which participants had no problems with the items. Out of the 41 items, participants' responses indicated that there were no problems with 30 (73%) of the items.

4.4.5.3.1 Not Applicable

Five items were noted to be not applicable to participants' circumstances. For example, a participant noted she thought her symptoms could be a sign of illness, but not because she had been ill often, but rather symptom interpretation was prompted by her past [cancer] experience and the advice given by her healthcare professional.

> *"I thought it could be a sign of illness because I'm often ill, erm well I'm not often ill but I've, since having a cancer diagnosis I've had a few scares, erm so that's why I thought there might be something to be done and also the pain in my leg erm I though well you don't have an unexplained pain, and also my consultant, my cancer consultant has said if you have a symptom lasting*

longer than three weeks go and see the doctor. Ah, so I did think it could be a sign of illness but not because I was often ill. I'm going to put neither agree nor disagree." (Question 38 - P1)

4.4.5.3.2 Incongruent Response

There were no incongruent responses between written and verbal responses.

4.4.5.3.3 Different Question

Only one participant answered a different question to the one being asked. The participant noted that it took him some time before deciding that something needed to be done about his symptoms.

"I thought something needed to be done about my symptoms. Well eventually I did do something, I did think something needed to be done but it was quite a while before I actually did anything, erm so I'm going to put agree for that." (Question 30, P1)

4.4.5.3.4 Confusion

Two participants indicated that they did not fully understand the content of the item. For example, one participant was confused about integrating the stem with the item

"At the start? Okay, so this always pre-fixes everything does it? [Interviewer: Yeah, so at the start…] Okay. I thought it was normal… get better on their own. Erm neither agree nor disagree. Someone like me to… that someone like me should get this symptom, what's the question exactly? Someone like me to get this symptom?" (Question 13 - P2)

4.4.5.3.5 Missing implications

None of the items were omitted.

4.4.5.3.6 Repeated Question

One participant (P1) repeated the question for two items and another participant (P2) stumbled over three items. For example:

"I thought people at my age do not get this type of symptom. Erm… do not get this type of symptoms. This is a negative

question so I'm going to have to think about this. Erm, I mean I do think people at my age might well get this type of symptom so I think I'm going to disagree with that." (Question 11 - P1)

Table 47 Frequency and type of problems identified for the four respondents for Version Two and Version Three

	Version 2 (72 items)	**Version 3 (41 items)**
Type of Problem		
No problems	220 (76%)	151(92%)
Not applicable	2 (1%)	5 (3%)
Incongruent response	7 (2%)	0 (0%)
Different question	3 (1%)	1 (1%)
Confusion	3 (1%)	2 (1%)
Missing	39 (14%)	0 (0%)
Repeated question	15 (5%)	5 (3%)
Total	**288**	**164**

4.5 Content Validation of Version Three

Given that significant changes were made to the PaTH-Q since the initial content validation (Version One), a second round of content validation was carried out as suggested by Polit et al. (2007). This second round was conducted simultaneously with the face validation of Version Three of the PaTH-Q.

4.5.1 Aim

The aim of this study was to establish the content validity of the PaTH-Q (Version Three) to:

1. determine which elements of the instrument are relevant to and representative of the targeted construct, namely heuristics and reasons to consider help-seeking;
2. to refine, remove and add items prior to final questionnaire preparation and administration.

4.5.2 Methods

4.5.2.1 Participants

Experts, who had been approached in the first round and who provided their consensus to take part in a potential second round, were contacted and invited to participate via email. This methodology was based on Lynn's (1986) rationale who suggested that the same experts can be used for a second round.

Consequently, the email that was used to solicit and encourage participation, outlined why the individual was chosen as an expert reviewer for round two and what their participation would entail (see **Appendix 22** for a copy of the email). Attached to the email was a revised version of the PaTH-Q (Version Three). Furthermore, the email also included a link to the online expert review rating form[27] which experts were asked to fill out if they were happy to serve as an expert reviewer for the second round (see **Appendix 23** for a copy of the online rating form). Identical to the first round, the online rating form provided experts with a conceptual definition for heuristics and 'cognitive reasons to consider help-seeking'. Experts were also asked to rank items based on their representativeness, clarity, as well as being asked to state whether an item should be deleted. At the end of the rating form experts were also asked to rate the comprehensiveness of the entire questionnaire and state whether they thought that there were any constructs that the questionnaire missed.

An online rating form, instead of a mailed paper form, was chosen for the second round, because 1) it would encourage more timely responses and 2) the format of Version Three was more user friendly and easier to administer online than the previous version.

12 experts were invited to take part, 10 of whom had taken part in the first round of content validation. Again, experts were given one month to complete the package, with a reminder being sent after two weeks asking experts to complete and return the package if they had not yet done so.

4.5.2.2 Data Analysis

As in the previous round the content validity of the questionnaire package was determined by calculating the CVI at the I-CVI and S-CVI/Ave level. Further to this, the item and subscale clarity index, and whether items should be deleted was also established.

4.5.3 Results

All 12 (100%) experts took part in the second round of content validation.

Details on the item representativeness, item clarity and qualitative responses can be found in **Table 48** to **Table 56**.

[27] The online rating form was hosted by Qualtrics. Qualtrics is an online research tool that allows users to create and host online surveys. All questionnaire data were stored securely on their servers.

4.5.3.1 Item Representativeness

All of the items for *Rate of Change rule, Age-Illness rule, Novelty rule* and *Duration rule* had I-CVIs above the recommended level of 0.78. The majority of items for *Symmetry rule*, apart from two items (Number 31 and 32, I-CVI = 0.75) were above the recommended level. Further, two items for *Severity rule* (Number 8 and Number 10), one for *Pattern rule* (Number 19) and *Optimistic Bias rule* (Number 37) had an I-CVI of 0.75.

All of the subscales had an S-CVI/Ave above the recommended limit of 0.80.

For 'cognitive reasons to consider help-seeking' both the I-CVIs and S-CVI/Ave were above the recommended levels.

4.5.3.2 Item Clarity

All of the items for *Rate of Change, Age-Illness rule, Novelty rule, Duration rule, Symmetry rule* and *Optimistic Bias rule* had item clarity indices above the recommended level of 0.78. All of the items for *Severity rule*, apart from two items (Number 8, item clarity index = 0.75; Number 9, item clarity index = 0.73; Number 10, item clarity index = 0.67) were above the recommended level. Further, one item for *Age-Illness rule* (Number 13, item clarity index = 0.75), one for *Pattern rule* (Number 21, item clarity index = 0.75) and *Symmetry rule* (Number 31, item clarity index = 0.75) had item clarity indices below 0.78.

All of the subscales (*Rate of Change rule, Age-Illness rule, Novelty rule, Pattern rule, Duration rule, Symmetry rule* and *Optimistic bias rule*), with the exception of *Severity rule*, had scale clarity indices above the recommended limit of 0.80.

For 'cognitive reasons to consider help seeking' all of the items, apart from one item (Number 41, item clarity index = 0.75) were above the recommended level.

4.5.3.3 Comprehensiveness of the PaTH-Q

In response to the question 'Do you think the questionnaire represents the entire domain of heuristics?' 11 (92%) experts answered 'yes', whereas one expert answered 'no'.

4.5.3.4 Qualitative Responses

Qualitative feedback from expert reviewers raised three types of issues. Firstly, expert reviewers suggested that some items should be re-worded to make items clearer and easier to understand, for example because they sounded confusing.

Secondly, a number of reviewers commented that some items do not make sense if they are preceded by 'At the start…'.

Thirdly, experts suggested that for some heuristics, for example *Severity rule*, the items were about impact rather than severity and tapped into the extreme end of severity. As such, new items were generated for *Severity rule* in order to ensure that they would cover the full range of the definition.

Table 48 Rate of Change rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
1	My symptoms seemed to get better	1.00	0.98	0.92	0.92	n = 2	
2	My symptoms were getting worse	1.00		1.00		n = 1	
3	My symptoms changed slowly or not at all	1.00		0.92		n = 2	**P2:** should item 3 be two items? Slowly/ not changing are different to me. You have the opposite in item 4 so why not change 3 to just no change **P3:** Items 3 and 4 could probably be excluded as concept covered well with other items. I have some concerns about using 'At the Start' for the beginning string for all items. It doesn't really fit eg at the start my symptoms were getting worse. you could actually drop at the start from many of these and the items would be more relevant
4	My symptoms changed quickly	1.00		0.83		n = 2	
5	I got more and more symptoms	0.92		0.83		n = 2	**P5:** For Q5 the wording seems a little ambiguous - perhaps find an alternative for 'more and more' for example just 'more'
6	My symptoms started suddenly	1.00		1.00		n = 2	**P1:** Number 6 is difficult to understand but is capturing a useful construct. Can you re-word? If so it would become a Yes.

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
							P2: should item 3 be two items? Slowly/ not changing are different to me. You have the opposite in item 4 so why not change 3 to just no change 6) should this developed rather than started? **P9:** In 6) the use of 'start' and 'started' is repetitive. Is there another word you could use, 'appeared'? **P10:** I'm not sure about the final one: a sudden start isn't necessarily a continued change. It's a single change (from 0 to 1, whereas we are more trying to capture continued change)

Table 49 Severity rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
7	I could still do my everyday activities	0.92	0.81	0.92	0.77	n = 1	
8	I was still able to get out of bed	0.75		0.75		n = 5	**P10:** Q8, presupposes you were in bed when it began. Q9 unable to eat is severe; what about eating less?
9	I was unable to eat	0.83		0.73		n = 2	
10	I was unable to move	0.75		0.67		n = 4	**P3:** Item 10 does not add much to item 8 and is less clear.
Additional Comments/Items:		**P2:** All these items are about impact not severity.... I think you need to decide what you want here **P5:** I like these! **P7:** Only concern is that you have 4 items of which three represent very severe limitations which might lead to highly skewed distributions. Minor tweaking to the wording to make it easier to agree with at a lower level of impairment might be helpful -- e.g., 'at the start I was _sometime_ unable to eat' **P9:** 8,9,10 all seem to be at the very severe symptom end. I'm sure you've considered this I just wondered if you might wish an item that suggested struggling to do everyday activities or having reduced appetite or mobility? Perhaps I've misunderstood the purpose.					

Table 50 Age-Illness rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
11	I thought people at my age do not get this type of symptom	0.92	0.94	0.92	0.92	n = 3	
12	I thought my symptoms were just due to age rather than illness	1.00		1.00		n = 0	
13	I thought it is normal for someone like me to get this symptom	0.83		0.75		n = 3	**P1:** 13 would be ok with re-wording e.g. I thought it was normal for someone of my age to get this symptom **P9:** 13) does not refer to age just 'someone like me', people may not consider age when answering.
14	I did not expect to get this symptom at my age	1.00		1.00		n = 2	
Additional Comments/Items:		**P7:** Something to note is that answers are age dependent which could make interpretation if score different – e.g., someone aged 20 would be responding to essentially a different question than someone aged 70 because you refer to 'my age'					

Table 51 Novelty rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
15	My symptoms seemed unusual	1.00	1.00	1.00	1.00	n = 0	**P5:** For Q15 I am just wondering about 'unusual' - can something be unusual but not novel? Would 'unusual for me' work?
16	My symptoms were similar to symptoms I had in the past	1.00		1.00		n = 2	
17	I did not expect to have these symptoms	1.00		1.00		n = 1	**P9:** 17) I'm not sure expecting is the right word. Do we expect symptoms? Is that the same as novelty? **P10:** Q17; almost by definition a symptom is 'abnormal' so the answer to this should always be 'yes'.
18	I thought my symptoms were common	1.00		1.00		n = 2	

Table 52 Pattern rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
19	I was in pain	0.75	0.93	0.92	0.92	n = 3	
20	My symptoms were only mild	1.00		1.00		n = 1	
21	My symptoms were easy to notice	0.92		0.75		n = 6	
22	My symptoms were vague	1.00		1.00		n = 1	
23	My symptoms were striking	0.92		0.83		n = 2	
24	My symptoms were really severe	1.00		1.00		n = 2	

Table 53 Duration rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
25	I thought my symptoms would get better on their own	0.92	0.95	1.00	0.95	n = 1	**P10:** Q25-26 is prognostication, not duration
26	I thought my symptoms would be short lived	0.92		1.00		n = 1	
27	I thought my symptoms were coming and going	1.00		0.92		n = 2	
28	My symptoms lasted longer than I expected	1.00		0.92		n = 2	
29	My symptoms were persistent	0.92		0.83		n = 3	**P10:** At the start, they can't be persistent or longer than expected - because it's at the start. I think you have to remove 'at the start'
Additional Comments/Items:		**P3:** Same problem with 'At the start'. It doesn't work when you are asking about duration and change over time.					

Table 54 Symmetry rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
30	A friend or family member had similar symptoms which turned out to be signs of illness	0.83	0.83	0.92	0.88	n = 2	**P3:** Item 30. 'a serious illness' perhaps item 31. may be better to say they were like symptoms in a health campaign
31	My symptoms were different to those I saw in a health campaign	0.75		0.75		n = 3	**P5:** Q31 - would everyone understand 'health campaign'. What about posters or TV adverts about illness? **P7:** regarding 31, presupposes someone saw a health campaign. Might be better to be less specific and give health campaign as an example: 'At the start my symptoms were different to those I expected. e.g. saw in a health campaign' regarding 32, might be clearer to add 'At the start _I thought_ I understood my symptoms' **P8:** not sure if all people will know what you mean in 31 **P10:** Q31; why choose 'different' to a health campaign? Wouldn't 'similar' be simpler?
32	I understood my symptoms	0.75		0.83		n = 3	
33	I did not know what had triggered my symptoms	1.00		1.00		n = 0	
Additional Comments/Items:		**P9:** Overall, I'm unsure about this rule/heuristic and its clarity. I think the individual items are ok but I don't think the overall heuristic is					

	clear.

Table 55 Optimistic Bias rule (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
34	It was unlikely to be a sign of illness, because I am generally a healthy person	1.00	0.90	0.92	0.85	n = 1	
35	I thought it could be a sign of illness, because I am often ill	1.00		0.83		n = 2	
36	I thought most symptoms are harmless	0.83		0.83		n = 2	
37	I thought most symptoms are a sign of illness	0.75		0.83		n = 4	
Additional Comments/Items:		**P1:** 'At the start' beginning every sentence can sometimes alter the meaning of what follows... **P8:** do you mean most of these/current symptoms or most symptoms in general?					

Table 56 Cognitive reasons to consider help-seeking (Round Two)

Q	Items	I-CVI	S-CVI/ Ave	Item Clarity	Subscale Clarity	Delete (Yes)	Qualitative Responses
At the start, …							
38	I thought my symptoms were serious	1.00	0.96	1.00	0.92	n = 0	
39	I thought something needed to be done about my symptoms	1.00		1.00		n = 1	
40	I thought nothing was wrong	1.00		0.92		n = 1	
41	My symptoms were normal	0.83		0.75		n = 4	

4.6 Development of Version Four of PaTH-Q

Minor modifications were made to Version Three (see **Appendix 19**) as outlined in **Table 57**. The main areas where changes were made to create Version Four are as follows:

The stem 'At the start…' was placed before every item as cognitive interviews indicated that participants sometimes ignored the stem completely when choosing their responses and instead appeared to only respond to items in a standalone manner when completing the PaTH-Q. McColl et al. (2001) suggest that if a remote scale format is used, as is the case with the PaTH-Q, the stem question should be repeated every three to four questions. However, expert reviewers suggested that the stem does not work for some of the items because they would have an impact on their meaning. Therefore, it was decided to exclude the stem for seven items.

Qualitative feedback from the content validation of Version Three suggested that some items should be reworded. Items were altered in line with the expert recommendations when content validity and clarity indices were below the recommended guidelines or when participants exhibited problems with these items in the cognitive interviews. This decision was made on the premise that the central aim of face validity is that it intends to assess the extent to which a target population finds the tool to be reasonable and comprehensible at face value (Nunnally & Bernstein, 1994).

The most substantial changes which were made to the PaTH-Q following analysis were for *Severity rule*. Even though, both stages of face validity did not highlight considerable problems with the items for this heuristic, I-CVIs were still below the recommended guidelines for two items (Number 2 and Number 4). Further, S-CVI/Ave and subscale clarity indices were also below the recommended guidelines, and qualitative feedback suggested that items tapped into impact rather than severity and appeared to be at the extreme end of symptom experience. Consequently, the items for this heuristic were replaced with selected items from the "European Organization for Research and Treatment of Cancer Quality of Life Questionnaire" (EORTC QLQ-C30) (Aaronson et al., 1993). It was hoped that this decision would enhance the validity of items as well as for the subscales. Nevertheless, further psychometric testing would be necessary to confirm whether this is actually the case.

Table 57 Modifications made to create Version 4

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
RATE OF CHANGE RULE							
1	My symptoms seemed to get better	No problems	No problems	Problems with the item (Missing – P5[29]; Repeated Question – P2; P5)	No problems	Problems with the item in Version 2 were resolved in Version 3	At the start, my symptoms seemed to get better
2	My symptoms were getting worse	No problems	Item should be re-worded and that stem does not fit the item	No problems	No problems	No changes made	At the start, my symptoms were getting worse
3	My symptoms changed slowly or not at all	No problems	Item should be excluded or split into two items	Problems with the item (Missing – P5)	No problems	Item amended 'At the start…' was not added to item, because it was decided that item would not make sense with the stem	My symptoms did not change

[28] 'At the start,…' was added to every item unless stated otherwise

[29] Participant P5 did not fill out Section One (Barriers to help-seeking) as he sought help immediately after noticing symptoms

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
4	My symptoms changed quickly	No problems	No problems	No problems	Problems with the item (Repeated Question)	No changes made, overall consensus was that the item was not problematic	At the start, my symptoms changed quickly
5	I got more and more symptoms	No problems	Item seems ambiguous	Original item [I was getting more symptoms] was amended. [30] Problems with the original item (Missing – P5)	No problems	No changes made	At the start, I got more and more symptoms
6	My symptoms started suddenly	No problems	Item should be re-worded	No problems with the item	No problems	No changes made	At first, my symptoms started suddenly
SEVERITY RULE							
7	I could still do my everyday activities	No problems	Items for this heuristic tap into the severe symptom spectrum	Problems with the item (Missing – P5; Incongruent response – P2)	No problems	Item amended	At the start, I was still able to pursue my hobbies or other leisure activities [31]

[30] Version Two amended when creating Version Three

[31] Items obtained from EORTC QLQ-C30 (Aaronson et al., 1993)

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
8	I was still able to get out of bed	Indices below recommended cut-off	Items for this heuristic tap into the severe symptom spectrum	Problems with the item (Not applicable – P2; Missing – P5)	No problems	Item amended	At the start, I was still able to do my work or other activities [31]
9	I was unable to eat	No problems	Items for this heuristic tap into the severe symptom spectrum	No problems with the item	No problems	Item amended	At the start, I had trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase [31]
10	I was unable to move	I-CVI below recommended guidelines Overall, qualitative feedback suggested that	Items for this heuristic tap into the severe symptom spectrum	No problems with the item	Problems with the item (Repeated Question – P2)	Item amended	At the start, I needed to rest
11						Item inserted as qualitative feedback from the expert reviewers indicated that items for this	At the start, I needed to stay in bed or a chair during the day [31]

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
						heuristic tap into the severe symptom spectrum	
AGE-ILLNESS RULE							
12	I thought people at my age do not get this type of symptom	No problems	No problems	Original item [People at my age do not get this type of symptom] was amended. No problems	Problems with the item (Not applicable – P4; P1 – Repeated Question)	No changes made, overall consensus was that the item was not problematic	At the start, I thought people at my age do not get this type of symptom
13	I thought my symptoms were just due to age rather than illness	No problems	No problems	Original item [I thought my symptoms were just due to age] was amended. [3] Problems with the item (Missing – P5; Incongruent Response – P2)	No problems	No changes made	At the start, I thought my symptoms were just due to age rather than illness
14	I thought it is normal for someone like me to get this	No problems	Item is not specific enough as individuals might not consider age	Original item [It is normal for someone like me to get this symptom] was	Problems with the item (Confusion – P4)	Item amended	At the start, I thought it is normal for someone my age

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
	symptom		when responding to the item	amended. [3] Problems with the item (Missing – P5)			to get this symptom
15	I did not expect to get this symptom at my age	No problems	No problems	No problems	No problems	At the start not added	I did not expect to get this symptom at my age
NOVELTY RULE							
16	My symptoms seemed unusual	No problems	Item should be re-worded	Original item was amended [My symptoms were unusual] [3] Problems with the item (Confusion – P4)	No problems	Item amended	At the start, my symptoms seemed unusual to me
17	My symptoms were similar to symptoms I had in the past	No problems	No problems	No problems	No problems	No changes made	At the start, my symptoms were similar to symptoms I had in the past
18	I did not expect to have	No problems	Qualitative feedback suggested	No problems	No problems	No changes made	At the start, I did not expect to

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
	these symptoms		problems with the item.				have these symptoms
19	I thought my symptoms were common	No problems	No problems	Original item was amended [My symptoms are common] [3] Problems with the item (Missing – P5)	No problems	No changes made	At the start, I thought my symptoms were common
PATTERN RULE							
20	I was in pain	No problems	No problems	No problems	Problems with the item (Not applicable – P4)	No changes made, overall consensus was that the item was not problematic	At the start, I was in pain
21	My symptoms were only mild	No problems	Item should be re-worded	Problems with the item (Missing – P5)	No problems	No changes made	At the start, my symptoms were only mild
22	My symptoms were easy to notice	No problems	Item should be re-worded	No problems	No problems	No changes made	At the start, my symptoms were easy to notice

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
23	My symptoms were vague	No problems	Item is not clear, appears problematic and should undergo further user testing.	Problems with the item (Missing – P5)	No problems	No changes made	At the start, my symptoms were vague
24	My symptoms were striking	No problems	Item is not clear and representative	No problems	No problems	No changes made	At the start, my symptoms were striking
25	My symptoms were really severe	No problems	Item might overlap with 'severity' heuristic	Item was generated following preliminary analysis of Version 2	No problems	No changes made	At the start, my symptoms were really severe
DURATION RULE							
26	I thought my symptoms would get better on their own	No problems	Stem [At the start…] does not work for items for this heuristic as it is asking about duration and change over time. Further, it was suggested that item	No problems	No problems	No changes made	At the start, I thought my symptoms would get better on their own

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
			is about prognostication				
27	I thought my symptoms would be short lived		Stem [At the start…] does not work for items for this heuristic as it is asking about duration and change over time. Further, it was suggested that item is about prognostication.	Problems with the item (Missing – P5; Different Question, P2)	No problems	No changes made	At the start, I thought my symptoms would be short lived
28	I thought my symptoms were coming and going		Stem [At the start…] does not work for items for this heuristic as it is asking about duration and change over time. Further, it was suggested that item is about	Problems with the item (Missing – P5; Incongruent Response – P2)	No problems	No changes made	At the start, I thought my symptoms were coming and going

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
			prognostication.				
29	My symptoms lasted longer than I expected	No problems	Stem [At the start…] does not work for items for this heuristic as it is asking about duration and change over time. Further, it was suggested that item is about prognostication.	Item was generated following preliminary analysis of Version 1	No problems	At the start not added	My symptoms lasted longer than I expected
30	My symptoms were persistent		Stem [At the start…] does not work for items for this heuristic as it is asking about duration and change over time. Further, it was suggested that item is illogical.	Problems with the item (Repeated Question – P5)	No problems	At the start not added	My symptoms were persistent

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
SYMMETRY RULE							
31	A friend or family member had similar symptoms which turned out to be signs of illness	No problems	One reviewer noted items are clear and representative, but questioned the clarity of the heuristic	Problems with the item (Incongruent Response – P5)	Problems with the item (Not applicable – P4; P1 – Repeated Question)	No changes made. At the start not added	A friend or family member had similar symptoms which turned out to be signs of illness
32	My symptoms were different to those I saw in a health campaign	No problems	Item should be re-worded as participants might have problems in understanding the item. One reviewer noted items are clear and representative, but questioned the clarity of the heuristic	Problems with the item (Missing – P5)	No problems	No changes made	At the start, my symptoms were different to those I saw in a health campaign
33	I understood my symptoms	I-CVI below recommended guidelines	One reviewer noted that the items are clear and	Problems with the item (Missing – P5; Confusion, P4)	No problems	Item amended	At the start, I thought I understood my

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
			representative, but questioned the clarity of the heuristic				symptoms
34	I did not know what had triggered my symptoms	No problems	One reviewer noted that the items are clear and representative, but questioned the clarity of the heuristic	No problems	No problems	No changes made	At the start, I did not know what had triggered my symptoms
OPTIMISTIC BIAS RULE							
35	It was unlikely to be a sign of illness, because I am generally a healthy person	No problems	One reviewer noted that the stem can sometimes change the meaning of item	Original item was amended [I am generally a healthy person][3] Problems with the item (Missing – P5; Repeated Question – P4)	No problems	No changes made	At the start, I thought it was unlikely to be a sign of illness, because I am generally a healthy person
36	I thought it could be a sign of illness, because I am	No problems	One reviewer noted that the stem can sometimes change the meaning of item	Original item was amended [I am often ill was amended]. [3]	Problems with the item (Not applicable – P1)	No changes made	At the start, I thought it could be a sign of illness, because I

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
	often ill			No problems			am often ill
37	I thought most symptoms are harmless	No problems	One reviewer noted that the stem can sometimes change the meaning of item	Original item was amended [Most symptoms are harmless][3] Problems with the item (Missing – P5)	Problems with the item (Confusion – P1)	Item amended	I think most symptoms are harmless
38	I thought most symptoms are a sign of illness	No problems	No problems	Original item was amended [Most symptoms are a sign of illness][3] Problems with the item (Different Question – P4; Repeated Question – P5)	No problems	Item amended	I think most symptoms are a sign of illness
COGNITIVE REASONS TO CONSIDER HELP-SEEKING							
39	I thought my symptoms were serious	No problems	No problems	No problems	Problems with the item (Not applicable – P1)	No changes made	At the start, I thought my symptoms were

Q	Content Validity of Version 3			Face Validity of Version 2	Face Validity of Version 3	Verdict	Final Items Version 4[28]
	Items	**Quantitative Findings**	**Qualitative Findings**	**Findings**	**Findings**		**Items**
							serious
40	I thought something needed to be done about my symptoms	No problems	No problems	No problems	Problems with the item (Different Question – P1; Repeated Question – P2)	No changes made	At the start, I thought something needed to be done about my symptoms
41	I thought nothing was wrong	No problems	No problems	Face Validity, Stage 1 highlighted problems with the item (Missing – P5)	No problems with the item	No changes made	At the start, I thought nothing was wrong
42	My symptoms were normal	No problems	No problems	Face Validity, Stage 1 highlighted problems with the item (Missing – P5, Incongruent Response – P2; Repeated Question – P4)	Problems with the item (Confusion – P3)	Item amended	At the start, I thought my symptoms were not normal

4.7 Discussion

This chapter outlined the steps taken to develop the initial item pool for the PaTH-Q and to establish the content and face validity of the PaTH-Q. Doing so helped to determine which elements of the PaTH-Q are relevant and representative of the construct to be measured. Further, the process also helped to determine which items should be refined, removed or added prior to administering the questionnaire to determine its psychometric properties.

The first stage involved drafting survey items using theoretical definitions and the qualitative data included in the secondary analysis (see Chapter Three) as well as choosing the appropriate response format in order to create Version One of the PaTH-Q. Following this, content validity of Version One was established via an expert panel. As a result of this process, items that were problematic due to their reverse nature were either deleted or reworded to avoid any double negatives in the PaTH-Q. Survey items with I-CVIs or item clarity indices below the recommended level of 0.78 were also deleted or edited. The same procedure was applied for subscales were the S-CVI/Ave and subscale clarity indices where below the recommended guidelines of 0.80. As part of the revision process, it was useful to have both the quantitative and qualitative feedback from experts. Without qualitative feedback it would have been difficult to determine how an item should be amended for it to become more adequate. For example, new survey items were designed in response to qualitative feedback from expert reviewers as experts had indicated that some items did not cover the full construct. As such, after the first stage of content validation an item was added to the *Pattern Rule* to ensure that items covered the full range of definition for this heuristic.

Following this, Version Two (and Version Three of the PaTH-Q) were subject to face validation and further content validation. Initial findings from the face validation study led to a change in the structure of the PaTH-Q in that there would only be one section as opposed to having one section on 'Barriers to seeking care' and another on 'Triggers to seeking care'. Some advantages of having one section instead of two are that it makes the PaTH-Q more user friendly and easier to administer. Further, a generic stem enables participants who perceive themselves to be someone who may seek help almost immediately after noticing symptoms to answer the PaTH-Q without skipping any sections. Indeed, the face validation of Version Three indicated far fewer problematic items than in Version Two. In addition, the second content validation round showed that figures for I-

CVIs, S-CVI/Aves and clarity indices increased after Section One and Section Two were combined. Nevertheless, one disadvantage of having only one section is that the various items will now have to be correlated with TTP, whereas before they directly asked about the factors that may have extended the appraisal interval (barriers to seeking help) and those which may have shortened the appraisal interval (triggers to seeking help) in relation to the theoretical model (Scott et al., 2013).

To create Version Four of the PaTH-Q implications from the content validation of Version Three, as well as face validation of Version Two and Three were analysed concurrently. This was done in order to ensure a comprehensive analysis so as to create a final version of the PaTH-Q that would encompass all the elements that are relevant and representative of the targeted construct. It was useful to analyse these data concurrently, because even though the I-CVI was fine for the majority of the items, experts' qualitative comments suggested that participants may struggle with the items. Further, face validity data could then be checked to see whether experts' assertion was accurate. This ultimately enabled items to be amended or left unchanged if they were understood by participants.

Specifically, Version Four of the PaTH-Q is a 42-item scale that examines eight different heuristics' (*Rate of Change rule, Age-Illness rule, Pattern rule, Duration rule, Symmetry rule, Optimistic Bias rule, Novelty rule* and *Severity rule*) and perceived reason(s) to discuss symptom with a HCP, specifically cognitive reasons (i.e. beliefs about symptoms, something is wrong/serious). Items are rated on a five-point Likert Scale ranging from "Strongly Disagree" to "Strongly Agree".

4.7.1 Strengths

There are a number of strengths to this study. For example, this study has taken a rigorous and systematic approach to the development of the PaTH-Q. Bollen (1989) noted that content validity is "a qualitative type of validity where the domain of concept is made clear and the analyst judges whether the measure fully represent the domain (p. 185). Firstly, the initial item pool was based on established psychological theory and the transcripts of patients talking about their symptom interpretation and decision to seek help. To ensure all of the items in the PaTH-Q are relevant and representative of the construct 49 in-depth [semi-structured] interviews of patients referred with symptoms suspicious of pancreas, colorectal, oral, respiratory, melanoma, breast, and prostate cancer were analysed. A directed content analysis approach and categorisation matrix underpinned by the concepts

and definitions within the 'appraisal' interval of the MPT (Scott et al., 2013) was used to explore the data. Doing so helped to inform the generation of pools of items that reflected the factors of the relevant theory in relation to symptom interpretation. Further, as outlined in this chapter, content validity was established by an expert panel of academic researchers, academic general practitioners (the majority of whom had an expertise in early cancer diagnosis) and a statistician with an expertise in psychometrics. To date, instrument developers have been criticised for their failure to conduct content and face validation studies following initial item generation (Haynes et al., 1995). For example, findings from the systematic review conducted as part of this thesis showed that when new instruments were developed, only 14% (n = 12/n = 35) demonstrated face validity and only 12% (n = 10/n = 35) demonstrated content validity. Consequently, it is hoped that by having established the content and face validity of the PaTH-Q, using the recommended procedures, that this will not only increase the likelihood that the items in the PaTH-Q are representative and relevant of the construct being measured, namely heuristics and 'cognitive reasons to consider help-seeking', but that it will also enhance the ease and understanding at which it is completed.

The cognitive interviews not only allowed any problems that individuals' may encounter when they fill out the PaTH-Q to be identified (and hopefully resolved), but also enabled refinement of the questionnaire by determining which items should be deleted. It is anticipated that by having established the face and content validity of the PaTH-Q this will further minimise any problems with the questionnaire.

4.7.2 Limitations

Expert feedback is a relatively subjective form of assessment. Consequently, the study is subject to any bias that may exist among experts. Nevertheless, analysis of the feedback showed that there appeared to be a consensus among experts concerning which items were not representative of the construct, should be deleted, were not clear, or too difficult to understand. For example, experts gave a lower rating for the majority of the items in the *Severity rule*, as indicated by representativeness and clarity indices. Experts also suggested that the items should be deleted as items were at the extreme end of symptom experience. Experts were also asked to suggest any additional items for the PaTH-Q. Consequently, these steps should have helped to minimise any limitations arising from the subjective nature of expert feedback.

Another limitation may be social desirability bias. Social desirability bias is defined as individuals' likelihood to answer questions in ways that they perceive being socially acceptable rather than meaningful (Krosnick & Presser, 2010). Social desirability may have influenced the responses in the cognitive interviews as the researcher was present in the room whilst participants completed the questionnaire. Even though the researcher sat out of sight and also told participants to pretend as if they were alone in the room, this may not have been enough to eliminate any potential social desirability bias.

The sample size for both stages of face validation was relatively small. Nevertheless, it is not unusual to use small samples in cognitive interviewing (Willis, Royston, & Bercini, 1991). Furthermore, to date there are no clear guidelines as to how many individuals should be interviewed. For example, to date the sample sizes of studies that have used the 'think aloud' method ranged from 19 (French et al., 2007) to 45 (Darker & French, 2009) participants. Furthermore, findings from the systematic review revealed that for studies that investigated how psychosocial factors affect help-seeking for [potential] symptoms of cancer, studies that used newly developed questionnaires the sample size for face validity if assessed ranged between n = 5 (Reifenstein, 2007) to n = 43 (Unger-Saldana et al., 2012).

Any changes made to the PaTH-Q following content and face validation may adversely impact reliability and validity. Ideally, Version Four of the PaTH-Q would need to undergo further validation testing to determine whether validity has been compromised at this stage. However, the only substantive change was made to items in the *Severity rule* for which three new items were generated following qualitative feedback and descriptive statistics, which indicated low indices for representativeness and clarity. Nevertheless, as these new items are based on an existing scale that has been previously tested for reliability and validity (Aaronson et al., 1993), namely the EORTC QLQ-C30, it is believed that these items will not have a negative impact on the PaTH-Q's performance.

4.7.3 Conclusions

The 42 item PaTH-Q promises to measure how numerous heuristics and 'cognitive reasons to consider help-seeking' influence symptom interpretation and TTP. However, further validation is needed to help establish the psychometric properties of the questionnaire, specifically its factor structure, reliability (internal consistency, item discrimination) and validity (discriminant, convergent, predictive, and construct).

Chapter 5 : Assessment of Psychometric Properties

5.1 Introduction

Chapter Four outlined the development process of the PaTH-Q and the steps taken to test and ensure the questionnaire's content and face validity. This chapter highlights the steps taken to further establish the psychometric properties of the PaTH-Q by determining aspects of reliability and validity. To do so the questionnaire (Version Four; **Appendix 24**) was administered to a sample of individuals previously diagnosed with cancer.

This chapter begins by providing an overview of the different aspects of reliability and validity that warrant consideration when aiming to establish the psychometric properties of a questionnaire.

5.2 Background

5.2.1 Reliability

Reliability is defined as the degree to which a measurement is able to consistently measure an attribute (DeVon et al., 2007). Reliability can be established via internal consistency and the test-retest method. Internal consistency which "is the extent to which items in a (sub)scale are correlated (homogenous), thus measuring the same construct" (Terwee et al., 2007, p.36). Given that internal consistency is unable to capture whether an instrument is reproducible over time it has been suggested that other measures of reliability such as test-retest reliability should be established and/or considered as a measure of stability (Streiner et al., 2015).

5.2.1.1 Test-retest reliability

For test-retest reliability to be established, respondents are asked to complete the same questionnaire twice at two different time points. A questionnaire is said to be reliable if the results are consistent between the two different time points. However, there are several disadvantages to test-retest reliability. For example, it is costly and time consuming as the questionnaire needs to be administered on several occasions in order to compare the results. Also, the likelihood that respondents will provide the same answers is increased as they are already familiar with the questionnaire. Given that the test-retest method is time consuming, it was not carried out as part of this doctoral thesis. However, it has been performed as part of a wider project by an intercalated BSc in Psychology student

(supervised by SK and SS; see **Appendix 25**). Therefore, only internal consistency and its components will be discussed in further detail in this chapter.

5.2.1.2 Internal Consistency

Internal consistency is the degree to which items are related to each other (also known as homogeneity) (Schmitt, 1996). An instrument is said to be internally consistent if its items are highly intercorrelated. Higher inter-item correlations indicate that all items are measuring the same thing. As such, a unidimensional scale should consist of a set of items that correlate well with each other (DeVellis, 2011). Nevertheless, although internal consistency is of importance it is not an adequate enough indication of homogeneity and unidimensionality (Briggs & Cheek, 1986; Cortina, 1993). Rather, an internally consistent (unidimensional or homogeneous) instrument is obtained through adequate construct definitions and items, as well as by conducting a factor analysis to determine whether the items which make up an instrument form one scale or multiple ones (Terwee et al., 2007).

Once the number of homogeneous (sub)scales has been determined, via factor analysis, Cronbach's alpha should be calculated for each (sub)scale (Terwee et al., 2007). DeVellis (2011) noted that an alpha of 0.70 is an acceptable range for measures, whereas according to Nunnally and Bernstein (1994) values between 0.70 and 0.90 indicate good internal consistency. Terwee et al. (2007) who recommended quality criteria for measurement properties of health status questionnaires gave a positive rating for internal consistency when factor analysis was conducted and Cronbach's alpha ranged between 0.70 and 0.95. Nevertheless, instead of exclusively relying on alpha, John and Benet-Martínez (2000), for instance, argue that alpha should be interpreted with reference to inter-item correlations and scale length, and the extent to which these fit the construct being measured. Consequently, the construct being measured is an important parameter when interpreting alpha (Clark & Watson, 1995; Schmitt, 1996).

It has been argued that alpha may be flawed in its ability to point toward internal consistency. This is because it is a function of two parameters: the number of items in a scale and the intercorrelations between items (Cortina, 1993; Cronbach, 1951). Therefore, a high alpha can be achieved if a scale has many items or items that are highly inter-correlated, or a combination of the two. Attempting to enhance internal consistency by reducing items will most likely result in a scale that has limited content. If a scale is more limited than the construct it aims to measure then validity will be compromised.

Similarly an alpha value over 0.80 or 0.90 for short scales does not necessarily mean that a scale is reliable, but rather that the item domain may be redundant and limited. For example, such scales may contain items that are in effect paraphrases of each other and although such items can inflate alpha they do not necessarily add valuable information and can be dismissed without risking losing any valuable information. This is also referred to as the attenuation paradox. One cannot ensure construct validity simply by increasing the internal consistency of a measure beyond a certain degree. Doing so may have an adverse impact on validity when added items only focus on one part of the construct whilst dismissing the remainder (John & Benet-Martínez, 2000).

In addition to the aforementioned points, Osborne (2014) noted further elements that jeopardise alpha. Firstly, it is not possible to have accurate estimates of alpha when the analysis encompasses items that contain negative item-total correlations. Consequently, items expected to have a negative item-total correlation should be reversed before any analysis is carried out. Secondly, alpha assumes that all items make up a single construct. If this assumption is violated it will not be possible to obtain a correct estimate of alpha.

5.2.2 Validity

Validity refers to the extent to which a questionnaire measures what it is supposed to measure (DeVellis, 2011). According to DeVellis (2011) “validity is inferred from the manner in which a scale was constructed, its ability to predict specific events, or its relationship to measures of other constructs” (p. 59). According to the author there are three types of validity that relate to these procedures:

1. Content validity
2. Construct validity
3. Criterion-related validity

Content validity was discussed, tested and established in Chapter Four. The latter two types of validity will be discussed in further detail in this chapter.

5.2.2.1 Construct validity

Construct validity is “the degree to which an assessment instrument measures the targeted construct (i.e., the degree to which variance in obtained measures from an assessment instrument is consistent with predictions from the construct targeted by the instrument).” (Haynes et al., 1995, p. 240). It is confirmed if the items in question are related to its

defined theory and concepts. For example, the PaTH-Q which intends to measure heuristics and 'cognitive reasons to consider help-seeking' would demonstrate construct validity if all the items in the questionnaire measure concepts that are indeed elements of heuristics and 'cognitive reasons to consider help-seeking'.

According to Cronbach and Meehl's (1955) influential work on construct validity three factors should be considered when examining construct validity, namely 1) it is essential to define theoretical models and their correlations, 2) means to measure the hypothetical constructs defined by the theory need to be developed, and 3) the hypothesised associations between variables (and their observable indices) need to be examined. Further and similarly, Goodwin and Goodwin (1991) noted that the following elements are required in order to establish construct validity: 1) forming hypotheses based on the theoretical foundation of the construct, 2) designing a study so that the hypothesis can be tested, 3) collecting and analysing data, and 4) determining if the findings support the hypothesis or not. One of the principles of construct validity is that the theoretical concept underlying the content domain being measured should support, modify or reject the theory (Goodwin & Goodwin, 1991). There are multiple ways to determine construct validity. These are outlined below:

5.2.2.1.1 Factor Analysis

Even though factor analysis is only one method that can be applied to determine whether a scale accurately measures a construct (Froman, 2001), a paper published by Goodwin and Goodwin (1991) revealed that factor analysis is one of the most popular techniques used to establish construct validity. Nevertheless, the authors criticised the use of factor analysis as not being sufficient enough to determine construct validity. Instead numerous hypotheses, which would relate to divergent, convergent and discriminant validity, or the impact of interventions on respondents' scores, should be stated and tested (Goodwin & Goodwin, 1991).

One of the aims of factor analysis is that it reduces a large set of variables into a smaller set. It also creates separate underlying dimensions (these separate dimensions are commonly known/referred to as subscales) between the measured variables and latent constructs. This enables theory to be formed and refined (Floyd & Widaman, 1995)..

Factor analysis can be regarded as a two stage process. This is especially the case if it is applied when developing measures and when it pertains to construct validity. Froman

(2001) noted that the first stage of factor analysis is Exploratory Factor Analysis (EFA). EFA techniques are applied when there are no assumptions about the underlying factor structure of a measure, such as the number of factors and their mutual correlations. This permits the exploration of underlying dimensions to generate a theory from a set of latent construct presented by a set of items. The second stage, known as Confirmatory Factor Analysis (CFA) is carried out when there is a prior hypothesis, based on theory or previous analyses, to investigate if the data fit a prearranged factor structure (Floyd & Widaman, 1995). Following the first stage of factor analysis, during which items will either be discarded or retained and interpreted, CFA is usually performed. Ideally, CFA should be performed on a new dataset, which might be obtained by dividing the actual dataset into two. This means that EFA will be performed on one half of the data, whereas CFA will be performed on the remainder. Nevertheless, given that this requires a relatively large sample size, CFA is usually performed on a new dataset for which data were collected after an initial EFA. In CFA the following elements are examined: how the factors are organised in a larger model, hypotheses about the factors, the extent to which factors are able to explain an underlying construct and parameter estimates (Froman, 2001).

One of the disadvantages of EFA is that it may fail to reveal the actual dimensions of a construct. This may especially be the case if the scale contains items for which the theoretical model was not adequately defined (Froman, 2001). In order to avoid this from happening, it is of importance that researchers have a theoretical rationale as to why they wish to compute a factor analysis. For example, the theoretical rationale should be based on concepts about how the construct in question will perform. Further, Froman (2001) argues that items should not be included in the analysis unless the researcher knows what the domain of interest is.

In terms of the appropriate number of items required for a factor analysis Guilford (1952) suggested that at least three items are required to define a factor. However, a minimum of 5 items per factor may be more beneficial as it accounts for the possible deletion of items should findings reveal low inter-item correlation on a factor (Froman, 2001; Fabrigar & Wegener, 2012).

5.2.2.1.2 Extreme groups

In extreme groups, two groups that are known to be high and low in the construct being measured are sampled [Streiner et al. (2015) note that this is also referred to as

discriminative validation and is not to be confused with discriminant validity]. For example, one group will have the behaviour or trait whereas the other group will not. The mean score of the groups should differ significantly in the expected direction if the instrument is valid (DeVon et al., 2007). For instance, a questionnaire that measures fear of hypoglycaemia should cause different responses in a group of insulin users after a hypo as opposed to individuals who did not experience one (Bradley, 1994).

5.2.2.1.3 Convergent and Divergent validity

Hypothesis testing is based on a theoretical framework and indicates the expected direction of scores on a measure. Construct validity is supported if the scores reflect the measure as hypothesised (DeVon et al., 2007). Convergent validity, a sub-type of construct validity, refers to the extent to which the new instrument is related to other variables and other instruments that measure a related construct. Regarding convergent validity, although the new instrument should correlate highly with other measures of the similar construct, it should not correlate too highly. This is especially the case, if it was hypothesised that the new instrument measures a characteristic that has not yet been measured by existing instruments.

Divergent correlation (also referred to as discriminant validation; Streiner et al., 2015) is the notion that a questionnaire measuring a certain construct should not correlate with scales that measure dissimilar or unrelated constructs. For example, if a hypothesis notes that anxiety is independent of intelligence the findings should not reveal a strong correlation between the two elements (Streiner et al., 2015).

One way to determine convergent and divergent validity is via the multitrait-multimethod (MT-MM). The method can be used whenever two or more traits, are being measured with two or more methodologies. A matrix will portray the degree of correlation and the relationships between traits. Different measures of a similar or theoretically related construct should correlate highly with each other and different constructs should show low correlation with each other. If possible, a new instrument should be corroborated against instruments that are maximally different. This means that a self-administered questionnaire should be evaluated against one that is completed by a performance or observer task as opposed to a different self-administered questionnaire. The idea behind this reasoning is that scores on a measure are not only dependent on the characteristic being measured, but also dependent on how it is being measured (Streiner et al., 2015). However, validation studies using the MT-MM method are frequently not feasible due to

the time required on the participant's part and the problems associated with finding different methods of assessing a similar attribute (Streiner et al., 2015).

5.2.2.1.4 Criterion-related validity

Criterion-related validity is the extent to which findings obtained by the questionnaire under measurement correlate with a 'gold standard' (Streiner et al., 2015). Terwee et al. (2007) who, as mentioned earlier, recommended quality criteria for measurement properties of health status questionnaires gave a positive rating to studies that provided substantial evidence that a measure is indeed a 'gold standard'. Furthermore, correlations between the 'gold standard' and the (new) instrument under measurement should be at least r = 0.70. However, the Scientific Advisory Committee of the Medical Outcomes Trust (2002) noted that criterion related validity is infrequently determined in the field of health status questionnaires due to the lack of established criterion measures. Moreover, the findings obtained via criterion-related validity can be impaired by inadequate sample size. For instance, sampling errors will be comparatively large and the statistical power of the inferential procedures used to analyse data from the validation study may be weakened when validity coefficients are assessed in small samples (Crocker & Algina, 1986). Specifically, if N is between 30 to 50, a predictor that has a satisfactory validity level in the population may only demonstrate an acceptable validity level in the sample being tested up to a third of the time. Accordingly, an N of 200 or more will be required to achieve validity level that will accurately reflect the validity level in the population 90% of the time (Schmidt, Hunter & Urry (1976) as cited in Crocker and Algina, 1986).

Criterion-related validity is comprised of predictive and concurrent validity. Predictive validity involves longitudinal associations and is the extent to which scores on a measure predict outcomes on some future criterion. A measure will be a valid predictor of the given criteria if the original measure and the criterion variable are highly correlated (Waltz, 2005). Concurrent validity, on the other hand, involves cross-sectional correlations where the questionnaire is correlated with a criterion measure (Streiner et al., 2015). For example, if the concurrent validity of an intelligence test were to be determined the researcher would correlate it with other valid intelligence tests (Kline, 2000). Nevertheless, as Kline (2000) acknowledged, this approach also highlights the problem associated with concurrent validity, because if a 'gold standard' measure already exists then developing a new measure is somewhat of a pointless task.

In terms of establishing criterion related validity for the PaTH-Q, establishing concurrent validity would not be feasible [the absence of a 'gold standard' was highlighted in Chapter Two].

5.3 Aims and Objectives

This study aimed to establish psychometric properties of a newly developed questionnaire (the PaTH-Q), with people who have previously been diagnosed with cancer. Specifically, the aim of this study was to establish the:

1. reliability of the PaTH-Q. This would be achieved by determining item-total correlations and internal consistency via Cronbach's alpha;
2. validity of the PaTH-Q, specifically which elements of the questionnaire are relevant to and representative of the targeted construct, from the perspective of questionnaire respondents. This would be achieved by determining construct validity, specifically hypothesis testing to confirm convergent validity.

5.4 Methods

5.4.1 Study design and participants

A cross-sectional design, using a retrospective questionnaire, was used for this study. Participants were recruited via the Macmillan Cancer Voices network, Cancer Research UK's (CRUK) involvement network and Pancreatic Cancer UK's (PCUK) involvement network and asked to fill out the questionnaire online or by paper, according to their preference. These networks provide user involvement groups for people previously diagnosed with cancer who would like to get involved in research or other volunteering opportunities. Specifically, CRUK placed an advert on the involvement opportunities section of their website[32] and in their newsletter which was sent to members electronically via email or hard copy. Similarly, PCUK's Involvement Network placed an advert in their monthly newsletter which was sent to members electronically. Macmillan Cancer Voices posted an advert on their Volunteering Village opportunities board[33]. All the advertisement mediums contained a brief summary of the study, as well as instructions on how to access the study information sheet, plus details on how to contact the researcher to ask further questions or

[32] http://www.cancerresearchuk.org/support-us/volunteer/patient-involvement-at-cancer-research-uk/involvement-opportunities

[33] https://volunteering.macmillan.org.uk/

to indicate their desire to take part in the study (see **Appendix 26** for a copy of the involvement opportunity that was posted on the Macmillan Cancer Volunteering Village opportunities board).

CRUK's Research Network has approximately 640 members who receive their newsletter[34], approximately 80 members receive a newsletter from PCUK, and approximately 2000 individuals are registered on the Macmillan Cancer Volunteering Village opportunities board. Thus, approximately 2 720 individuals potentially had access to the study details. Nevertheless, it should be noted that these user involvement channels do not only consist of members who had experiences of detecting [potential] symptom(s) of cancer, which consequently led to self-presentation to a HCP, but also consist of individuals whose cancer was detected via the asymptomatical screening route, as well as family members and carers of individuals' previously diagnosed with cancer; therefore, making these individuals ineligible for inclusion.

5.4.2 Eligibility

Eligible participants were individuals who 1) were previously diagnosed with cancer, 2) were over the age of 18 (no upper age limit), and 3) experienced symptoms prior to being diagnosed (as opposed to the diagnostic process being instigated by screening). People who were unable to understand English and those who were asymptomatic were not included in the study as the questionnaire has only been written in English and is focused on features of symptoms and beliefs about symptoms.

5.4.3 Procedure

The study flowchart is outlined in **Figure 22**.

Individuals who were willing to participate were asked to contact the researcher to express their interest in taking part. Potential participants were then sent an email (see **Appendix 27**) that contained further details about the study, a link to the questionnaire, their unique participant ID number[35] (a unique ID number was used instead of their name in accordance with the guidelines outlined by the Data Protection 1998), as well as a copy of the information sheet (see **Appendix 28**). Participants were also given the option to complete

[34] It is not known how many individuals on average visit the involvement opportunities section of the CRUK website

[35] The unique ID number was generated by www.researchrandomizer.org

the questionnaire on paper or online. The online questionnaire was hosted by Qualtrics. Qualtrics is an online research tool that allows users to create and host online surveys. All questionnaire data were stored securely on their servers. An online administration mode was chosen because, compared with traditional administration modes, such surveys have several advantages, such as shorter transmitting time, less delivery cost, more design options, and less data entry time (Fan & Yan, 2010). Furthermore, an online questionnaire was suitable for this study as all the advertisements were online, with the exception of the CRUK newsletter which was sent to participants using a hard copy. Participants willing to take part were asked to read the information sheet prior to participation. Prior to completing the questionnaire, participants were asked to confirm they met the study inclusion criteria (see **Appendix 29**). Those who were interested in taking part in the study but who did not meet inclusion criteria were thanked for their time. Screening data and contact details were then destroyed for those individuals. Completion of the questionnaire implied informed consent, as outlined in the information sheet. If participants failed to complete the questionnaire after two weeks of it being sent, they were sent a reminder email. To thank participants for their time, they were sent a £10 Amazon gift voucher upon completion of the questionnaire.

Ethical approval was obtained on 31st October 2016 by King's College London Research Ethics Office (LRS-16/17-3769) (see **Appendix 30**).

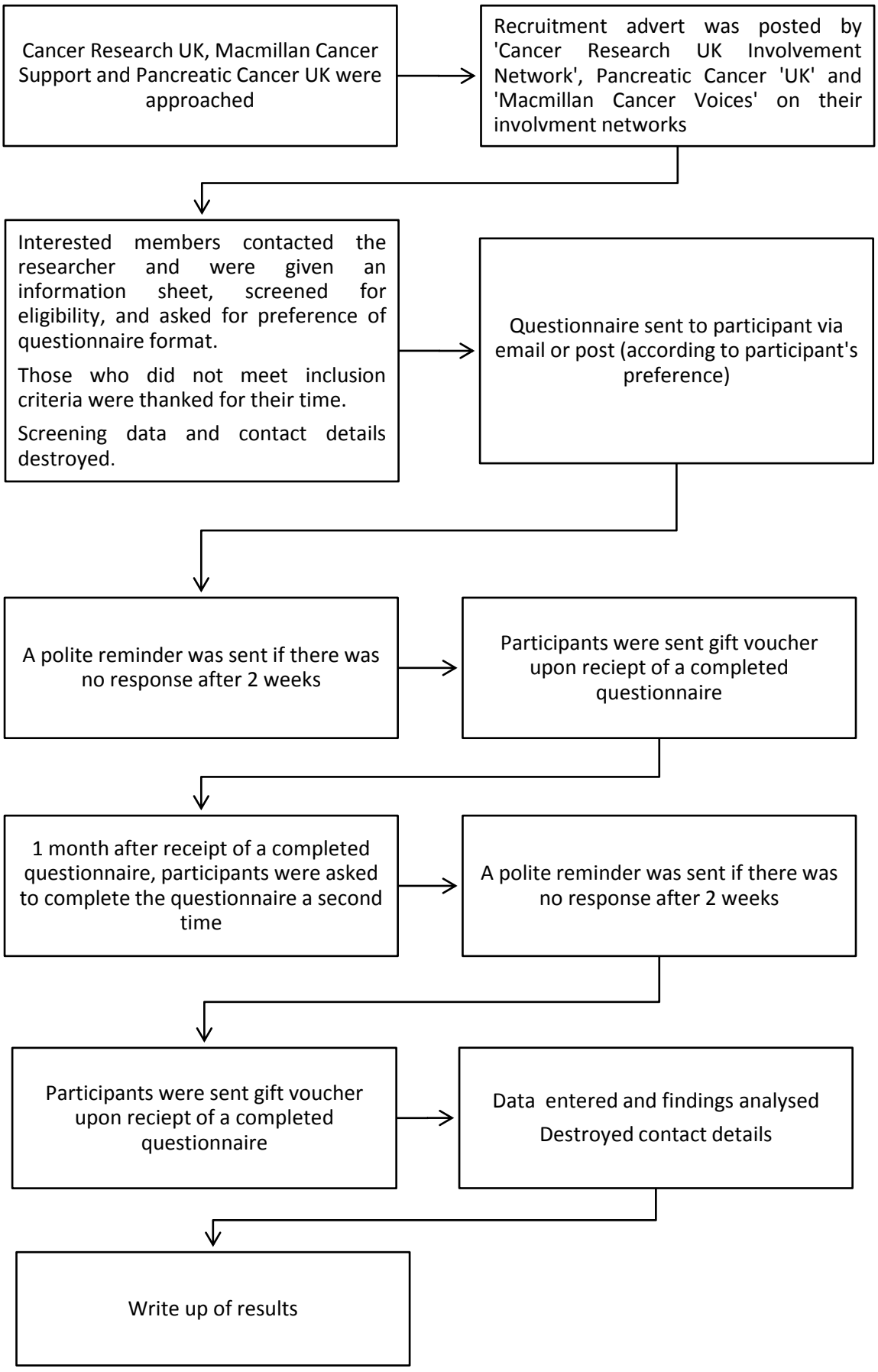

Figure 22 Study Flowchart

5.4.4 Materials

The online survey consisted of the following measures:

5.4.4.1 Pathways to Healthcare Questionnaire (PaTH-Q):

The PaTH-Q, the self-administered questionnaire to be used with patients who have sought help for (potential) cancer symptoms to retrospectively assess the factors that contributed to their decision to seek help, was used in this study. Specifically, the PaTH-Q examines the extent to which eight different heuristics (*Rate of Change rule, Age-Illness rule, Pattern rule, Duration rule, Symmetry rule, Optimistic Bias rule, Novelty rule, Severity rule*) and 'cognitive reasons to consider help-seeking' occurred at the time they first noticed symptoms. The PaTH-Q consists of nine subscales, eight of which are heuristics subscales and one sub-scale concerns 'cognitive reasons to consider help-seeking' (i.e. beliefs about symptoms). Items are rated on a five-point Likert Scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"). The barrier-keyed items (items 1, 6, 39, 8, 31, 13, 36, 17, 11, 22, 26, 18, 28, 12, 25, 42, 16, 7, 35) were reverse scored prior to computing total scores for each subscale and before conducting any psychometric analyses. After reverse scoring has been carried out for relevant items, high scores for each heuristics category reflect more triggers to seeking help/perceived need for care, whereas low scores reflect more cognitive barriers to seeking help/perceived need for care. For 'cognitive reasons to consider help-seeking' high scores reflect more cognitive reasons to seeking help whereas low scores reflect fewer cognitive reasons to seeking help.

5.4.4.2 Symptom Distress Scale

The "Symptom Distress Scale" (Meechan et al., 2003) was used to examine emotional distress when people first noticed symptoms. Participants rated emotional distress by the extent they felt each of the following five items, "anxious; afraid; distressed; concerned; scared" when first noticing their symptoms. Items were rated on a five-item Likert scale from 1 ('not at all') to 5 ('very much') and summed to produce a symptom emotional distress scale. Cronbach's alpha was $\alpha = 0.89$ in the original study (Meechan et al., 2003) and ranged from $\alpha = 0.88$ to $\alpha = 0.94$ in five studies that used (a modified version of) the 'Symptom Distress Scale' (Forghieri et al., 2010; Friedman et al., 2006; O'Mahony & Hegarty, 2009, O'Mahony et al., 2013; Scott et al., 2008). In the current sample Cronbach's alpha was $\alpha = 0.82$.

5.4.4.3 Time to Presentation

TTP was determined by asking individuals to indicate which symptoms they thought were related to their recent referral to hospital, when they first noticed a specific symptom (as indicated by the exact or estimated date), when they first considered telling a GP, nurse or dentist and when they first told their GP, nurse or dentist about it (as indicated by the exact or estimated date). These questions were previously used in the SYMPTOM study (e.g. Birt et al., 2014; Hall et al., 2015). These dates were collected in order to calculate TTP, and the duration of the appraisal and help-seeking intervals. Nevertheless, given that the responses to 'When did you first think about telling your GP, nurse or dentist about your symptom(s)?' and 'When did you first tell your GP, nurse or dentist about your symptom(s)?' were either missing or were not properly reported by participants, TTP could not be calculated. As such, only the amount of time that had passed since individuals first noticed symptoms was calculated by determining the amount of time (in years) that had passed between when individuals first noticed symptoms and when they had filled out the PaTH-Q.

5.4.4.4 Patient characteristics

Individuals were asked to provide details relating to their cancer type, age, gender, ethnicity, marital status, highest educational level, living arrangements and employment status.

5.5 Analysis

5.5.1 Missing data analysis

Missing data analysis were performed to determine if there was a pattern of missing values among items for the heuristics and 'cognitive reasons to consider help-seeking' categories' of the PaTH-Q.

According to the literature, missing data are a common (Duffy, 2006; Fox-Wasylyshyn & El-Masri, 2005) and problematic occurrence as it has an adverse impact on the external validity of findings as results may not be generalisable (Fox-Wasylyshyn & El-Masri, 2005). In self-administered questionnaires, missing data can occur at either the item (when a respondent does not answer one or more items on a questionnaire that measures an abstract variable or concept) or variable level (when all items on a questionnaire are missing).

Regarding the steps that should be taken in order how to best deal with missing data, different solutions have been put forward. For example, Tabachnick and Fidell (2001) suggested that variables should be deleted if missing values are affecting only a few variables and those variables are not necessarily required for any further analysis. Different suggestions concerning the cut-off for missing data have been recommended. Schafer (1999) suggested 5% as the cut-off for missing values (as cited in Schlomer, Bauman, & Card, 2010). Whereas, Raymond and Roberts (1987) suggested deleting variables when 40% or more of the data are missing.

If there were missing items subscale scores were prorated prior to performing correlation analyses to determine the construct validity of the PaTH-Q. This was done by using the following formula (Webster, Cella, & Yost, 2003):

Prorated subscale score = [sum of item scores] x [N of items in subscale] ÷ [N of items answered]

Prorating was only performed if more than 50% of the items were answered (Webster, Cella, & Yost, 2003). For example, for the *Rate of Change rule*, which consists of 6 items, a minimum of 4 items had to be answered.

5.5.2 Item means

Descriptive statistics were calculated for all the items of the PaTH-Q at the item level.

5.5.3 Reliability

5.5.3.1 Internal Consistency

As outlined earlier on in this chapter, Terwee et al. (2007) noted that the factor structure of a questionnaire ought to be established prior to determining internal consistency. A minimum sample size of 210 participants would have been required in order to perform an EFA based on Gorsuch's (1983) suggestion of a subject to variable ratio of 5:1. According to Comrey and Lee's (1992) guidance a sample size of 210 would be considered as "fair". Nevertheless, although a large sample size is a desirable precursor to computing factor analysis; it has been argued that with very well-conditioned data, a sample size of less than 50 can sometimes lead to reasonable findings (Fabrigar & Wegener, 2012). Thus, the suitability of the data were assessed to determine whether an EFA might be possible despite the small sample size. However, findings from the Kaiser-Meyer-Olkin (KMO) Test

for Sampling Adequacy and Bartlett's Test of Sphericity indicated that the requirements to perform an EFA were not met (see **Appendix 31**).

Internal consistency calculations were performed without an EFA based on the rationale that the PaTH-Q is 1) based on a theoretical model, namely the MPT (Scott et al., 2013) and 2) content validity of Version 3 of the PaTH-Q was supported by S-CV/Ave, which ranged from 0.78 to 1.00, and I-CVI, which ranged from 0.70 to 1.00 (see Chapter Four). Content validity is an important determinant of construct validity as it is the degree to which elements of a measure are relevant to and representative of the targeted construct (Haynes et al., 1995).

While it was not possible to determine the factor structure of the PaTH-Q due to insufficient sample size, it was decided to calculate the internal consistency, specifically item-total correlations and Cronbach's alpha using theoretically constructed subscales.

Following, Nunnally and Bernstein's (1994) recommendations each subscale would be considered reliable if the Cronbach's alpha coefficient is above 0.70. If the overall Cronbach's alpha coefficient for a subscale was less than 0.70 and when there were items with low item-total correlations then these items were removed from the scale. Authors such as Streiner et al. (2015) or Ferketich (1991) noted that correlations below r = 0.30 are not sufficiently related and therefore are considered weak measures of the construct under measurement and items that correlate over r = 0.70 are redundant.

5.5.4 Validity

Following removal of poorly discriminating items via examinations of internal consistency the resulting scales were assessed for validity as follows:

5.5.4.1 Convergent Validity

According to the CSM (Leventhal et al, 1984) individuals will have an emotional response to health threats in line with their interpretation. Consequently, the extent to which eight different heuristics (*Rate of Change rule, Age-Illness rule, Pattern rule, Duration rule, Symmetry rule, Optimistic Bias rule, Novelty rule, Severity rule*) were associated with emotional response to the discovery of symptoms (as measured by the "Symptom Distress Scale"; Meechan et al., 2003) was examined via a Pearson's correlation. High scores for each heuristics category would reflect attribution to illness or a perceived need for care and as such it was hypothesised that higher heuristics scores would be associated with

more emotional distress. Similarly, for 'cognitive reasons to consider help-seeking' high scores reflect a higher perceived need for care and as such it was hypothesised that higher scores would also be associated with more emotional distress.

The MPT/CSM also postulates that individuals will perceive cognitive reasons for discussing symptoms with a HCP (defined as beliefs about symptoms, e.g. something is wrong/serious) as a result of the symptom appraisal process underpinned by heuristics. Thus, as mentioned in Chapter Four (page 213), heuristics precede 'cognitive reasons to consider help-seeking'. Consequently, the extent to which the different heuristics (*Rate of Change rule, Age-Illness rule, Pattern rule, Duration rule, Symmetry rule, Optimistic Bias rule, Novelty rule, Severity rule*) were associated with 'cognitive reasons to consider help-seeking' was examined. High scores for each heuristics category reflect more cognitive triggers to seeking help / attribution to illness and as such it was hypothesised that higher scores would be associated with more perceived cognitive reasons to seek help.

A sample size calculation was carried out to determine how many individuals were required to conduct a Pearson's correlation for construct and predictive validity. The sample size calculation was conducted in GPOWER using an alpha of 0.05, a power of 0.80, and a medium effect size (p = 0.30) for a two-tailed test. To calculate the sample size for a Pearson's correlation, power analysis was conducted using software for estimating power of a bivariate normal model correlation. Based on the aforementioned assumptions, the required sample size was determined to be 67. Prior to computing any correlations, tests for normality (precisely Kolmogorov-Smirnov) were performed to check if data were normally distributed.

5.6 Results

Study recruitment took place from 11th November 2016 to January 31st 2017. **Figure 23** illustrates the sample size at each stage of recruitment and analysis.

5.6.1 Response rates

As shown in **Figure 23**, 64 individuals expressed their interest in completing the questionnaire. Following screening for exclusion criteria, 60 individuals were eligible to participate. Nevertheless, 10 participants opted to not complete the PaTH-Q, leaving a final sample size of 50 participants.

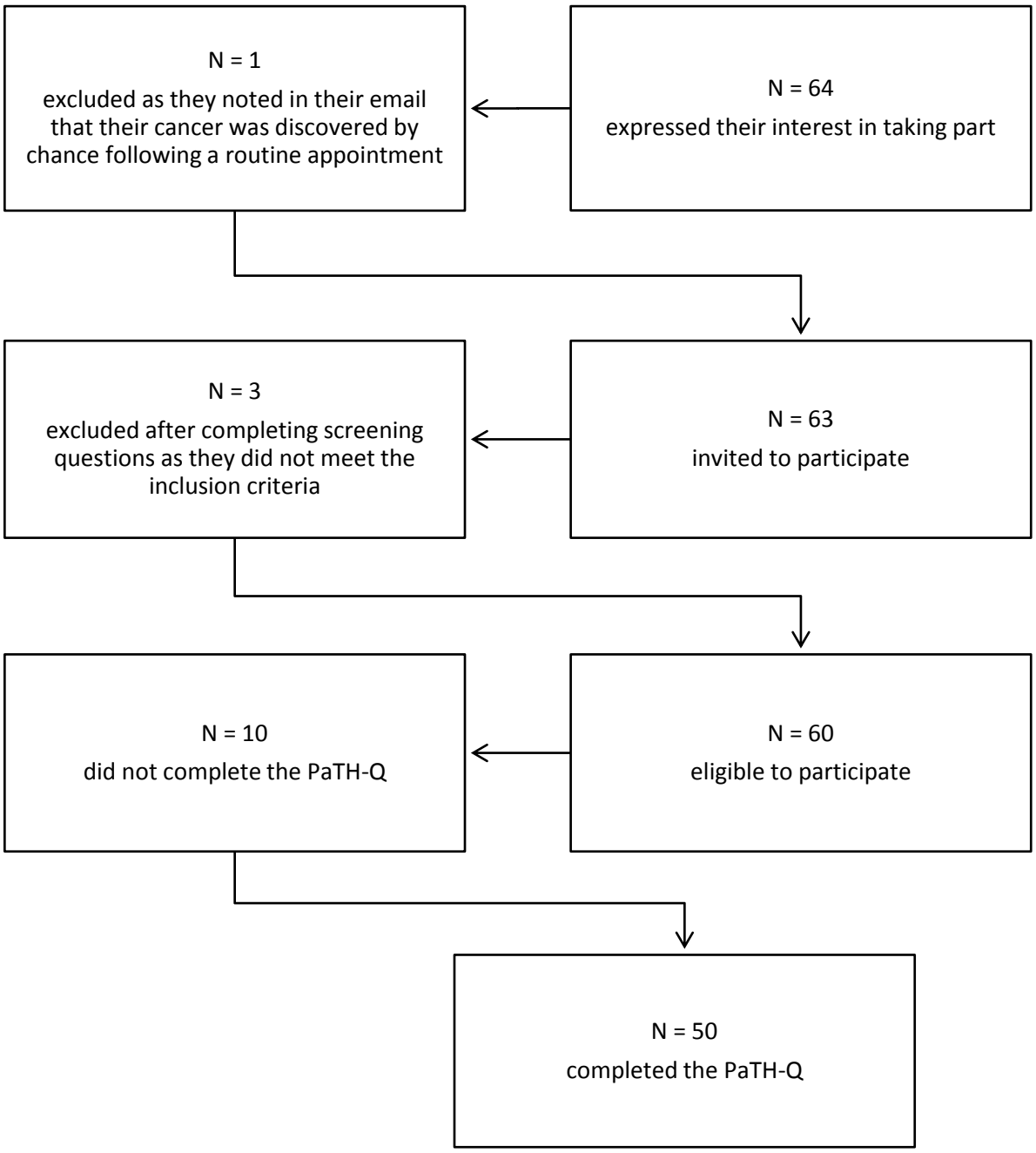

Figure 23 Sample size at each stage of recruitment and analysis

5.6.2 Patient Characteristics

The demographic information of the participants is presented in **Table 58**. Participants ranged in age from 26 to 73 years and had a mean age of 52.3 (SD = 10.82) years. The majority of participants were female (n = 37, 74%), whereas 13 individuals were male (26%).

As illustrated in **Table 59**, the most common cancer type was breast cancer (n = 14, 28%), followed by gynaecological cancers (n = 6, 12%), head and neck cancer (n = 6, 12%) and bowel cancer (n = 5, 10%).

In terms of the events leading to a cancer diagnosis, 43 (86%) had symptoms or noticed a change in their body and went to see a GP/family doctor/dentist or nurse. 7 (14%) individuals, on the other hand, had symptoms or noticed a change in their body and attended Accident and Emergency (A&E).

Table 58 Participants' demographic information

Participant demographics		N = 50	%
Age Group (years)			
	20 – 29	1	2 %
	30 – 39	6	12 %
	40 – 49	11	22 %
	50 – 59	20	40 %
	60 – 69	7	14 %
	> 70	4	8 %
	Missing*	1	2 %
Gender			
	Female	37	74%
	Male	13	26 %
Ethnicity			
	White British	46	92 %
	White Irish	1	2 %
	Any other white background	3	6 %
Education			
	Degree (or equivalent)	24	48 %
	Diploma (or equivalent)	4	8 %
	A'Level	8	16 %
	GCSE / O'Level	8	16 %
	Other	6	12 %
Employment status			
	Employed full-time	10	20 %
	Employed part-time	11	22 %

Participant demographics		N = 50	%
	Self-employed full-time	4	8 %
	Self-employed part-time	2	4 %
	Retired	11	22 %
	Permanently sick/disabled	4	8 %
	Temporarily sick/disabled	1	2 %
	Looking after family/home	2	4 %
	Other	5	10 %
Time since first noticing symptoms			
	< 1 year	7	14 %
	1 year – 2 years	8	16 %
	> 2 years	34	68 %
	Missing	1	2 %

Table 59 Cancer Types

Cancer Type	N = 50	%
Bile Duct	1	2 %
Bladder	1	2 %
Bowel	5	10 %
Brain	1	2 %
Breast	14	28 %
Gynaecological	6	12 %
Haematological	4	2 %
Head and Neck	6	12 %
Kidney	2	4 %
Lung	2	4 %
Melanoma	1	2 %
Other	1	2 %
Pancreatic	2	4 %
Prostate	1	2 %
Soft tissue sarcoma	1	2 %
Testicular	1	2 %
Thyroid	1	2 %

5.6.3 Missing data analysis

Table 60 shows the proportion of missing values for each item of the PaTH-Q. Overall, findings showed that 10 (23.81%) items had missing values and that 7 (14%) participants had missing values.

The questionnaire item that had the highest number of missing values was "My symptoms were persistent" [*Duration rule*] (n = 4 items, 8%) for the heuristics category. The remainder of the items (n = 41) had missing values of 4% or less (n = 2 items or less).

Table 60 Missing values for the heuristics and 'cognitive reasons to consider help-seeking' subscales of the PaTH-Q

Items	Missing Values
Rate of Change Rule	
[1] At the start, my symptoms seemed to get better	1 (2%)
[6] My symptoms did not change	1 (2%)
[14] At the start, my symptoms were getting worse	–
[15] At the start, I got more and more symptoms	–
[19] At the start, my symptoms changed quickly	–
[24] My symptoms started suddenly	–
Pattern Rule	
[2] At the start, I was in pain	2 (4%)
[11] At the start, my symptoms were only mild	–
[22] At the start, my symptoms were vague	–
[29] At the start, my symptoms were striking	–
[32] At the start, my symptoms were easy to notice	–
[40] At the start, my symptoms were really severe	–
Age-Illness Rule	
[3] I did not expect to get this symptom at my age	–
[5] At the start, I thought people at my age do not get this type of symptom	–
[13] At the start, I thought it is normal for someone my age to get this symptom	1 (2%)
[31] At the start, I thought my symptoms were just due to age rather than illness	–
Novelty Rule	
[4] At the start, my symptoms seemed unusual to me	2 (4%)
[17] At the start, my symptoms were similar to symptoms I had in the past	–
[27] At the start, I did not expect to have these symptoms	–
[36] At the start, I thought my symptoms were common	–

Items	Missing Values
Severity Rule	
[8] At the start, I was still able to pursue my hobbies or other leisure activities	1 (2%)
[9] At the start, I had trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase	–
[20] At the start, I needed to stay in bed or a chair during the day	–
[30] At the start, I needed to rest	1 (2%)
[39] At the start, I was still able to do my work or other activities	–
Optimistic Bias Rule	
[16] I think most symptoms are harmless	2 (4%)
[37] I think most symptoms are a sign of illness	–
[38] At the start, I thought it could be a sign of illness, because I am often ill	–
[42] At the start, I thought it was unlikely to be a sign of illness, because I am generally a healthy person	–
Symmetry Rule	
[12] At the start, my symptoms were different to those I saw in a health campaign	–
[25] At the start, I thought I understood my symptoms	–
[33] At the start, I did not know what had triggered my symptoms	–
[34] A friend or family member had similar symptoms which turned out to be signs of illness	–
Duration Rule	
[10] My symptoms were persistent	4 (8%)
[18] At the start, I thought my symptoms would be short lived	–
[33] At the start, I thought my symptoms would get better on their own	–
[23] My symptoms lasted longer than I expected	–
[34] At the start, I thought my symptoms were coming and going	–
Cognitive reasons to consider help-seeking	
[7] At the start, I thought nothing was wrong	–
[21] At the start, I thought my symptoms were not normal	–
[35] At the start, I thought something needed to be done about my symptoms	–
[41] At the start, I thought my symptoms were serious	1 (2%)

5.6.4 Mean scores for the heuristics and 'cognitive reasons to consider help-seeking' subscales of the PaTH-Q

Table 61 shows the mean scores and standard deviations for each item of the heuristics and 'cognitive reasons to consider help-seeking' subscales of the PaTH-Q.

With regard to the heuristics category, for *Rate of Change rule*, the item with the highest mean was 'At the start, my symptoms seemed to get better' (M = 3.92; SD = 1.12), while the lowest was 'At the start, I got more and more symptoms' (M = 2.52, SD = 1.11).

The highest mean score for *Pattern rule* was 'At the start, my symptoms were easy to notice' (M = 3.62, SD = 1.18), while the lowest was 'At the start, I was in pain' (M = 2.35, SD = 1.50).

The item 'At the start, I thought my symptoms were just due to age rather than illness' (M = 3.82, SD = 1.27) had the highest mean score for *Age-Illness rule*, whereas 'At the start, I thought people at my age do not get this type of symptom' (M = 2.56, SD = 1.07) had the lowest score.

For *Novelty rule*, 'At the start, my symptoms seemed unusual to me' (M = 3.71, SD = 1.17) had the highest mean score, while the lowest mean score was 'At the start, I thought my symptoms were common' (M = 2.96, SD = 1.05).

For *Severity rule* the highest mean score was 'At the start, I needed to rest' (M = 2.04, SD = 1.17), whereas the item with the lowest mean score was 'At the start, I needed to stay in be or a chair during the day' (M = 1.51, SD = 0.89).

The highest mean score for *Optimistic Bias rule* was 'I think most symptoms are harmless (M = 3.54, SD = 0.99), while the lowest was 'At the start, I thought it could be a sign of illness, because I am often ill' (M = 1.86, SD = 0.81).

In terms of the *Symmetry rule* [33] 'At the start, I did not know what had triggered my symptoms' had the highest mean score (M = 4.12, SD = 0.80), whereas the lowest mean score was for the item 'A friend or family member had similar symptoms which turned out to be signs of illness' (M = 1.90, SD = 1.17).

Finally, for *Duration rule*, the highest mean score was 'My symptoms were persistent' (M = 4.13, SD = 0.89), while the lowest was 'At the start, I thought my symptoms would be short lived' (M = 2.52, SD = 1.17).

For the 'cognitive reasons to consider help-seeking' subscale the item with the highest mean score was 'At the start, I thought my symptoms were not normal' (M = 3.58, SD = 1.11), whereas the item with the lowest score was 'At the start, I thought my symptoms were serious' (M = 2.49, SD = 1.29).

Table 61 Means and standard deviations for the heuristics and 'cognitive reasons to consider help-seeking' subscales of the PaTH-Q

Items	Mean (SD)	95% CI for Mean
Rate of Change Rule		
[1] At the start, my symptoms seemed to get better	3.92 (1.12)	3.60 – 4.24
[6] My symptoms did not change	3.06 (1.39)	2.66 – 3.46
[14] At the start, my symptoms were getting worse	2.98 (1.22)	2.63 – 3.33
[15] At the start, I got more and more symptoms	2.52 (1.11)	2.20 – 2.84
[19] At the start, my symptoms changed quickly	2.54 (1.11)	2.22 – 2.86
[24] My symptoms started suddenly	3.40 (1.33)	3.02 – 3.78
Pattern Rule		
[2] At the start, I was in pain	2.35 (1.50)	1.92 – 2.79
[11] At the start, my symptoms were only mild	2.42 (1.07)	2.12 – 2.72
[22] At the start, my symptoms were vague	3.00 (1.23)	2.65 – 3.35
[29] At the start, my symptoms were striking	3.16 (1.27)	2.80 – 3.52
[32] At the start, my symptoms were easy to notice	3.62 (1.18)	3.29 – 3.95
[40] At the start, my symptoms were really severe	2.36 (1.27)	2.00 – 2.72
Age-Illness Rule		
[3] I did not expect to get this symptom at my age	3.16 (1.10)	2.85 – 3.47
[5] At the start, I thought people at my age do not get this type of symptom	2.56 (1.07)	2.26 – 2.86
[13] At the start, I thought it is normal for someone my age to get this symptom	3.31 (1.18)	2.97 – 3.64
[31] At the start, I thought my symptoms were just due to age rather than illness	3.82 (1.27)	3.46 – 4.18
Novelty Rule		
[4] At the start, my symptoms seemed unusual to me	3.71 (1.17)	3.37 – 4.05
[17] At the start, my symptoms were similar to symptoms I had in the past	3.58 (1.28)	3.22 – 3.94
[27] At the start, I did not expect to have these symptoms	3.42 (1.11)	3.11 – 3.73
[36] At the start, I thought my symptoms were common	2.96 (1.05)	2.66 – 3.26
Severity Rule		
[8] At the start, I was still able to pursue my hobbies or other leisure activities	1.86 (1.12)	1.54 – 2.18
[9] At the start, I had trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase	1.98 (1.32)	1.54 – 2.18
[20] At the start, I needed to stay in bed or a chair during the day	1.51 (0.89)	1.25 – 1.77
[30] At the start, I needed to rest	2.04 (1.17)	1.71 – 2.37
[39] At the start, I was still able to do my work or other activities	1.78 (1.08)	1.47 – 2.09
Optimistic Bias Rule		
[16] I think most symptoms are harmless	3.54 (0.99)	3.25 – 3.83
[37] I think most symptoms are a sign of illness	2.66 (0.92)	2.40 – 2.92
[38] At the start, I thought it could be a sign of illness, because I am often ill	1.86 (0.81)	1.63 – 2.09

Items	Mean (SD)	95% CI for Mean
[42] At the start, I thought it was unlikely to be a sign of illness, because I am generally a healthy person	2.44 (1.11)	2.12 – 2.76
Symmetry Rule		
[12] At the start, my symptoms were different to those I saw in a health campaign	2.72 (1.07)	2.42 – 3.02
[25] At the start, I thought I understood my symptoms	2.78 (1.15)	2.45 – 3.11
[33] At the start, I did not know what had triggered my symptoms	4.12 (0.80)	3.89 – 4.35
[34] A friend or family member had similar symptoms which turned out to be signs of illness	1.90 (1.17)	1.57 – 2.23
Duration Rule		
[10] My symptoms were persistent	4.13 (0.89)	3.87 – 4.39
[18] At the start, I thought my symptoms would be short lived	2.52 (1.17)	2.19 – 2.85
[26] At the start, I thought my symptoms would get better on their own	2.74 (1.29)	2.37 – 3.11
[23] My symptoms lasted longer than I expected	3.72 (1.01)	3.43 – 4.01
[28] At the start, I thought my symptoms were coming and going	3.26 (1.30)	2.90 – 3.62
Cognitive reasons to consider help-seeking		
[7] At the start, I thought nothing was wrong	3.00 (1.28)	2.64 – 3.36
[21] At the start, I thought my symptoms were not normal	3.58 (1.11)	3.27 – 3.89
[35] At the start, I thought something needed to be done about my symptoms	3.54 (1.27)	3.18 – 3.90
[41] At the start, I thought my symptoms were serious	2.49 (1.29)	2.12 – 2.86

5.6.5 Reliability: Internal consistency

5.6.5.1 Item-total correlations

Table 62 shows item-total correlations each item of the heuristics and 'cognitive reasons to consider help-seeking' subscales of the PaTH-Q.

For *Rate of Change rule*, three items had an acceptable item-total correlation (r = 0.44 to r = 0.55). For *Pattern rule* four items had an acceptable item-total correlation (r = 0.54 to r = 0.59), while two appeared to be a weak measure of the construct (r = 0.15 to r = 0.19). For *Novelty rule* one item appeared to be a redundant measure of the construct (r = 0.76), whereas the other three items had an acceptable item-total correlation (r = 0.34 to r = 0.66). For *Optimistic Bias rule* three items had an acceptable item-total correlation (r = 0.38 to r = 0.57), whereas one item appeared to be a weak measure of the construct (r = 0.14). For *Duration rule* only two items had an acceptable item-total correlation (r = 0.35 to r = 0.43), while three were a weak measure of the construct (r = 0.15 to r = - 0.41). None of the

items for *Symmetry rule* had an acceptable item-total correlation, thus indicating that all of the items were weak measures of the construct. All the items had an acceptable item-total correlation for *Severity rule* (r = 0.58 to 0.69) and *Age-Illness rule* (r = 0.34 to r = 0.49).

For the 'cognitive reasons to consider help-seeking' subscale all of the items had an acceptable item-total correlation (r = 0.53 to 0.66).

5.6.5.2 Cronbach's alpha

As illustrated in **Table 62**, findings showed that for heuristics, *Novelty Rule* and *Severity Rule* had an alpha of 0.79 and 0.82 respectively. The remainder of the subscales (*Pattern rule, Age-Illness rule, Optimistic Bias rule, Symmetry rule and Duration rule*) had an alpha below 0.70. 'Cognitive reasons to consider help-seeking' had an alpha of 0.81.

Given the values from the item-total correlations and Cronbach's alpha, as a conservative decision it was decided to delete the relevant item from each subscale which had a low item-total correlation and where it was suggested that Cronbach's alpha would increase if that item were to be deleted. The items which were deleted as part of this procedure, prior to conducting any further analyses, were:

- At the start, my symptoms seemed to get better [*Rate of Change rule*]
- At the start, I was in pain [*Pattern rule*]
- At the start, I thought it could be a sign of illness, because I am often ill [*Optimistic Bias rule*]
- At the start, I thought my symptoms would get better on their own [*Duration rule*]

Following deletion of these items, the level of Cronbach's alpha increased for all of the subscales as illustrated in **Table 62**.

For the *Symmetry rule* all of the items appeared to be a weak measure of the construct. Given that internal consistency could not be established for the *Symmetry Rule* no further analyses were performed for this heuristic.

It was decided not to delete any item for *Age-Illness rule*, although the alpha for this scale was below the recommended level ($\alpha = 0.64$), as deletion of an item would have resulted in a lower alpha level and all the items had acceptable item-total correlations.

Table 62 Item-total correlations and Cronbach's alpha (if item deleted) for the heuristics and 'cognitive reasons to consider help-seeking' subscales of the PaTH-Q

Items	Item-total correlations	Cronbach's Alpha	Cronbach's Alpha if item deleted	Items to be deleted prior to any further analyses
Rate of Change Rule				
[1] At the start, my symptoms seemed to get better	-0.57	0.52	0.61	[1] At the start, my symptoms seemed to get better
[6] My symptoms did not change	0.26		0.49	
[14] At the start, my symptoms were getting worse	0.45		0.39	
[15] At the start, I got more and more symptoms	0.55		0.34	
[19] At the start, my symptoms changed quickly	0.44		0.40	
[24] My symptoms started suddenly	0.09		0.57	
Pattern Rule				
[2] At the start, I was in pain	0.15	0.68	0.74	[2] At the start, I was in pain
[11] At the start, my symptoms were only mild	0.54		0.60	
[22] At the start, my symptoms were vague	0.19		0.71	
[29] At the start, my symptoms were striking	0.55		0.59	
[32] At the start, my symptoms were easy to notice	0.59		0.58	
[40] At the start, my symptoms were really severe	0.57		0.58	
Age-Illness Rule				
[3] I did not expect to get this symptom at my age	0.34	0.64	0.61	None
[5] At the start, I thought people at my age do not get this type of symptom	0.43		0.56	
[13] At the start, I thought it is normal for someone my age to get	0.40		0.57	

Items	Item-total correlations	Cronbach's Alpha	Cronbach's Alpha if item deleted	Items to be deleted prior to any further analyses
this symptom				
[31] At the start, I thought my symptoms were just due to age rather than illness	0.49		0.51	
Novelty Rule				
[4] At the start, my symptoms seemed unusual to me	0.76	0.79	0.64	None
[17] At the start, my symptoms were similar to symptoms I had in the past	0.66		0.69	
[27] At the start, I did not expect to have these symptoms	0.34		0.85	
[36] At the start, I thought my symptoms were common	0.64		0.71	
Severity Rule				
[8] At the start, I was still able to pursue my hobbies or other leisure activities	0.69	0.82	0.76	None
[9] At the start, I had trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase	0.58		0.80	
[20] At the start, I needed to stay in bed or a chair during the day	0.56		0.80	
[30] At the start, I needed to rest	0.63		0.78	
[39] At the start, I was still able to do my work or other activities	0.63		0.78	
Optimistic Bias				
[16] I think most symptoms are harmless	0.57	0.61	0.40	[38] At the start, I thought it could be a sign of illness, because I am often ill
[37] I think most symptoms are a sign of illness	0.38		0.56	
[38] At the start, I thought it could be a sign of illness, because I am often ill	0.14		0.69	

Items	Item-total correlations	Cronbach's Alpha	Cronbach's Alpha if item deleted	Items to be deleted prior to any further analyses
[42] At the start, I thought it was unlikely to be a sign of illness, because I am generally a healthy person	0.51		0.45	
Symmetry Rule				
[12] At the start, my symptoms were different to those I saw in a health campaign	0.05	-0.12	-0.29	All items in the *Symmetry rule* were a poor measure of the construct and as such the scale will be discarded
[25] At the start, I thought I understood my symptoms	-0.14		0.11	
[33] At the start, I did not know what had triggered my symptoms	-0.03		-0.11	
[34] A friend or family member had similar symptoms which turned out to be signs of illness	-0.05		-0.09	
Duration Rule				
[10] My symptoms were persistent	0.16	0.27	0.21	[26] At the start, I thought my symptoms would get better on their own
[18] At the start, I thought my symptoms would be short lived	0.35		-0.03	
[26] At the start, I thought my symptoms would get better on their own	-0.41		0.60	
[23] My symptoms lasted longer than I expected	0.23		0.11	
[28] At the start, I thought my symptoms were coming and going	0.43		-0.15	
Cognitive reasons to consider help-seeking				
[7] At the start, I thought nothing was wrong	0.66	0.81	0.74	None
[21] At the start, I thought my symptoms were not normal	0.53		0.80	
[35] At the start, I thought something needed to be done about my symptoms	0.66		0.74	

Items	Item-total correlations	Cronbach's Alpha	Cronbach's Alpha if item deleted	Items to be deleted prior to any further analyses
[41] At the start, I thought my symptoms were serious	0.64		0.75	

5.6.6 Construct validity: Convergent validity

The tests for normality (Kolmorgov-Smirnov) indicated that data violated the assumptions of normality for ($p < 0.05$) for *Rate of Change rule, Novelty rule, Severity rule* and *Duration rule*. Therefore non-parametric tests, specifically Spearman's rank order test was performed to determine the association between *Rate of Change rule, Novelty rule, Severity rule, Duration rule* and 'cognitive reasons to consider help-seeking', whereas a Pearson correlation was performed for the heuristics that were normally distributed, namely *Pattern rule*, *Age-Illness rule* and *Optimistic Bias rule.* Normality tests also indicated that 'emotional response to symptom discovery' (as measured by the 'Symptom Distress Scale'; Meechan et al., 2003) was not normally distributed. Therefore, Spearman's rank order test was performed to determine the association between heuristics and 'emotional response to symptom discovery', as well as 'cognitive reasons to consider help-seeking' and 'emotional response to symptom discovery'.

5.6.6.1 Correlations between heuristics and 'cognitive reasons to consider help-seeking'

Table 63 shows the correlations between heuristics and 'cognitive reasons to consider help-seeking'. There was a large, significant, positive correlation between *Pattern rule* ($r = 0.50$; $p < 0.01$)*, Age-illness rule* ($r = 0.58$; $p < 0.01$)*, Optimistic Bias rule* ($r = 0.50$; $p < 0.01$) and 'cognitive reasons to consider help-seeking'. A moderate, significant, positive correlation was found for *Rate of Change rule* ($r_s = 0.39$; $p < 0.01$)*, Novelty rule* ($r_s = 0.36$; $p < 0.01$)*, Duration rule* ($r_s = 0.36$; $p < 0.01$) and 'cognitive reasons to consider help-seeking'. No significant association was found between *Severity rule* and 'cognitive reasons to consider help-seeking'.

Table 63 Convergent validity of the PaTH-Q subscales: Correlations between heuristics and 'cognitive reasons to consider help-seeking'

	Cognitive reasons to consider help-seeking	95% CI
Rate of Change Rule[b]	0.39**	(0.13-0.60)
Pattern Rule[a]	0.50**	(0.26-0.68)
Age-Illness Rule[a]	0.58**	(0.36-0.74)
Novelty Rule[b]	0.36**	(0.09-0.58)
Severity Rule[b]	0.16	(-0.12-0.42)
Optimistic Bias Rule[a]	0.50**	(0.26-0.68)
Duration Rule[b]	0.36**	(0.09-0.58)

Note: **p < .01

[a] Pearson Correlation, [b] Spearman Rank Order Correlation

5.6.6.2 Correlations between heuristics, 'cognitive reasons to consider help-seeking' and 'emotional response to symptom discovery'

Table 64 shows the correlations between heuristics, 'cognitive reasons to consider help-seeking' and 'emotional response to symptom discovery'. There was a medium, significant, positive correlation between *Rate of Change rule* (r_s = 0.44; p < 0.01)*, Pattern rule* (r_s = 0.40; p < 0.01)*, Age-Illness rule* (r_s = 0.44; p < 0.01)*, Novelty rule* (r_s = 0.33; p < 0.05)*, Severity rule* (r_s = 0.31; p < 0.05)*, Optimistic Bias rule* (r_s = 0.38; p < 0.01) and 'emotional response to symptom discovery'. Similarly, a large, significant, positive correlation was also found between 'cognitive reasons to consider help-seeking and 'emotional response to symptom discovery' (r_s = 0.61; p < 0.01). No significant association was found for *Duration rule* and 'emotional response upon symptom discovery'.

Table 64 Convergent validity of the PaTH-Q subscales: Correlations between heuristics, 'cognitive reasons to consider help-seeking' and 'emotional response to symptom discovery'

	Emotional Distress	95% CI
Rate of Change Rule	0.44**	(0.18-0.64)
Pattern Rule	0.40**	(0.13-0.61)
Age-Illness Rule	0.44**	(0.18-0.64)
Novelty Rule	0.33*	(0.05-0.56)
Severity Rule	0.31*	(0.03-0.54)
Optimistic Bias Rule	0.38**	(0.11-0.60)
Duration Rule	0.06	(-0.23-0.34)
Cognitive reasons to consider help-seeking	0.61**	(0.40-0.76)

Note: *p < .05, **p < .01

5.7 Discussion

The purpose of this study focused on the further validation of the PaTH-Q, specifically it aimed to establish reliability (internal consistency) and validity (convergent validity).

On the whole the items were well completed, with only 7 (14%) participants having missing values. The number of missing items was relatively low for each of the 10 questionnaire items that had missing data. Missing data has been attributed to questionnaire items being too sensitive, participants being unable to identify themselves with a question, unclear instructions or the questionnaire being too long (e.g. Kline, 2000). The low number of missing data further supports the findings from the face validity study (see Chapter Four) which indicated that participants did not regard the questionnaire as too sensitive, too long or as having unclear instructions. Rather it is suggested that missing data may have occurred because questions did not apply to participants or because they were missed in error.

The findings from this study indicate that the PaTH-Q has acceptable and good internal consistency for some of the heuristics categories and for 'cognitive reasons to consider help-seeking'. Acceptable levels of internal consistency were found for *Novelty rule* (Cronbach's α = 0.79) and *Pattern rule* (Cronbach's α = 0.74). *Severity rule* demonstrated good internal reliability (Cronbach's α = 0.82). The subscale 'cognitive reasons to consider help-seeking' also demonstrated good internal consistency (Cronbach's α = 0.81). The remainder of the subscales had questionable internal consistencies. **Table 65** provides a summary of the findings so far.

Table 65 Summary of findings for heuristics and 'cognitive reasons to consider help-seeking'

PaTH-Q subscales	Missing values	Cronbach's α	Convergent Validity	
			Cognitive reasons to consider help-seeking	Emotional response to symptom discovery
Rate of Change rule	Good	Questionable	Acceptable	Acceptable
Pattern rule	Good	Acceptable	Good	Acceptable
Age-Illness rule	Good	Questionable	Good	Acceptable
Novelty rule	Good	Acceptable	Acceptable	Acceptable
Severity rule	Good	Good	Questionable	Acceptable
Optimistic Bias rule	Good	Questionable	Good	Acceptable
Duration rule	Good	Questionable	Acceptable	Questionable
Cognitive reasons to consider help-seeking	Good	Good		Good

The PaTH-Q indicated moderate to strong convergent validity when examining the relationship between heuristics (which help individuals to appraise their symptoms and are a part of the process within the appraisal interval of the MPT) and 'cognitive reasons to consider help-seeking' (which are a cognitive representation of the threat (an element of illness representations) that is specifically about the perceived need for seeking help, and mark the event at the end of the appraisal interval).

At the moment, it may seem as if there is an overlap between some of the items for heuristics and some of the items for 'cognitive reasons to consider help-seeking'. For example, the item 'At the start, my symptoms seemed unusual to me', within the *Novelty rule* subscale appears to be similar to 'At the start, I my symptoms were not normal' from the 'cognitive reasons to consider help-seeking' subscale. Therefore, determining the construct validity of the PaTH-Q with the help of an exploratory factor analysis will be important as it will help to determine whether there might indeed be an overlap between items within the two concepts.

Large, positive associations were found for *Pattern rule*, *Age-Illness rule* and *Optimistic Bias rule,* whereas medium positive convergent validities were found for *Rate of Change rule*, *Novelty rule* and *Duration rule*. Medium, positive correlations were also found between heuristics (specifically *Rate of Change rule*, *Pattern rule*, *Age-Illness rule* and 'emotional response to symptom discovery', and convergent validity was supported for 'cognitive reasons to consider help-seeking' as indicated by the extent to which this subscale was associated with 'emotional response to symptom discovery'. These findings are in line with the hypotheses, given that the CSM (Leventhal et al., 1984) identifies an emotional response to health threats. However, construct validity may need to be confirmed once the factor structure is established and should be carried out alongside other validity tests, such as predictive and discriminant validity.

From the findings obtained so far, it appears that the subscales which show the most promising reliability and validity are *Pattern rule* and *Novelty rule* for the heuristics category. The subscale 'cognitive reasons to consider help-seeking' has also indicated promising reliability and validity. *Rate of Change rule*, *Age-Illness rule* and *Optimistic Bias rule* demonstrate satisfactory convergent validity, however the reliability of these scales is questionable.

Although *Severity rule* had only one missing value and good internal consistency, convergent validity findings appear to indicate that the perceived interference of symptoms did not necessarily lead to more 'cognitive reasons to consider help-seeking'. Again this may be attributed to study's small sample size, which prohibited a significant relationship to be found or it could indeed be the case that the level of interference of symptoms did not influence beliefs about symptoms as a perceived need for care. This opposes research which indicates the beliefs about the seriousness of symptoms are (partly) based on the extent to which symptoms interfere with daily activities (Elliott, McAteer, & Hannaford, 2011; Elliott et al., 2012). The *Duration rule* demonstrated acceptable levels of internal consistency. However, convergent validity findings indicate that the perceived duration of symptoms was not associated with emotional response upon symptom discovery. Again, this may be due to the small sample size or because emotional response to symptoms is based on something other than features of symptoms.

Although four items were deleted in order to increase Cronbach's alpha and prior to computing any further analyses to determine convergent validity it can be argued that if further validity testing is performed on the PaTH-Q in the future, specifically an EFA, these items might be input into the factor model and tested again. This is based on the rationale that while these items appeared to be a weak measure of the construct, the current findings may be biased by the study's small sample size.

Symmetry rule was omitted from any further analyses as Cronbach's alpha showed that the scale was unacceptable, regardless of whether an item wold have been deleted or not. Although findings from the content validity study indicated that the heuristic has both good I-CVI and S-CVI/Ave for Version Four, and the qualitative feedback from both experts and patients, across two rounds of content and face validity, did not indicate problems with this heuristic (see Chapter Four), the low alpha value may be because items in the scale are heterogeneous. Thus, whilst individual items may reflect the *Symmetry rule*/construct, the scale fails to do so. Nevertheless, given the study's small sample size, if further validity testing is performed this heuristic might be input into the model and tested again in order to establish whether it is indeed a weak measure of the construct.

Nevertheless, the present conclusions should be treated with caution given that a fundamental limitation on the conclusions drawn from this study is that the sample size was relatively small (N = 50), which ultimately impaired the ability of the study to draw strong conclusions.

5.7.1 Limitations

The sample size was inappropriate for computing an EFA given that the recommended sample size to perform this analysis was 210 participants. This was based on Gorsuch's (1983) as well as Comrey and Lee's (1992) recommendation who suggested that the STV ration should not be smaller than 5:1 and that a sample size of N = 200 is considered 'fair'. Given that the data were not suitable for factor analysis it is currently not known whether the PaTH-Q reflects two single underlying constructs, namely heuristics and 'cognitive reasons to consider help-seeking'. As such findings from the correlation analyses used to demonstrate convergent validity could be biased as this study was unable to demonstrate the construct validity of the PaTH-Q.

It can be argued that the low response rate for this study may be due to its administration mode. For example, a meta-analysis that examined the differences in response rates obtained between online questionnaires and other methods of administration revealed that online questionnaires are prone to an 11% lower response rate than other survey modes (Manfreda, Bosnjak, Berzelak, Haas, & Vehovar, 2008). Despite strategies employed to increase the response rate, such as offering a £10 Amazon voucher as an incentive, the response rate was poor. Several factors may have led to the low response rates. Firstly, given that the PaTH-Q aims to measure the psychosocial factors influencing symptom appraisal and help-seeking behaviour for (potential) symptoms of cancer the study was limited to individuals who had noticed symptoms themselves and subsequently decided to visit a HCP. The number of individuals who met these criteria and were registered to receive a newsletter by CRUK or PCUK and active members on the Macmillan volunteering village may indeed be very small. Secondly, even though participants were emailed a newsletter by the charities that contained an advert for the study, interested participants had to email the researcher to express their interest in the study. However, if participants would have been able to click on a link that directed them directly to the online questionnaire then this might have led to an increased response rate. Thirdly, if the researcher would have been able to directly send personalised emails to all members signed up to the patient involvement channels, rather than potential participants being asked to email the researcher, this may have also led to a higher response rate. However, due to data protection policies this approach was not possible. Personalised emails have been found to be a predictor of response rates for web surveys (e.g. Joinson & Reips, 2007).

The reliability findings should be interpreted with caution as these values might be an inaccurate reflection of how well or poorly the items in each subscale fit together. This is

because the factor structure of the PaTH-Q is currently unknown. The degree to which the items that make up a scale are correlated with each other (Terwee et al., 2007) is a necessary but not sufficient enough condition of homogeneity and unidimensionality (Clark & Watson, 1995). Moreover, high alpha values do not necessarily indicate internal consistency (John & Benet-Martínez, 2000). Thus, future work will need to be conducted in order to confirm or reject the Cronbach's alpha values. Moreover, as construct validity has not yet been established it is currently not known whether the low alpha values are due to 1) a heterogeneous construct, 2) too few questions or 3) poor inter-item correlations (Tavakol & Dennick, 2011). Similarly, it is currently not known whether the items that were suggested for deletion were indeed a weak measure of the construct being measured, or whether they were only a weak measure of the construct because of the study's relatively small sample size.

Another limitation to this study is that the study used a retrospective data collection approach. The majority of participants had not recently noticed their symptoms, with 34 participants (68%) indicating that they first noticed their symptoms more than two years ago. The time since symptoms were first noticed and thus the time since diagnosis could have resulted in participants being unable to accurately recall as to why they thought they needed to see a HCP. Time since diagnosis is an aspect that has been deemed to be an important issue that should be taken into account when sampling participants. The Aarhus statement, for instance, proclaimed that if participants were sampled too long after diagnosis recall bias will be more likely (Weller et al., 2012). Further, according to Hassan (2005), recall bias may be predictable in studies where the illness being studied is severe, such as cancer. Therefore, it can be argued that in order to minimise recall bias it would have been more beneficial to recruit patients who were recently referred with symptoms suggestive of cancer, for instance via the NHS's two week wait referral route.

5.7.2 Future work

Only convergent validity was established as part of this study. Yet for an instrument to be construct valid both convergent and discriminant validity should be established as only one of them is not sufficient enough to test construct validity (Trochim, 2006). Whilst the importance of establishing discriminant validity, for example via extreme groups, is acknowledged it was not possible to so in this study. However, this could be explored in future research by examining the extent to which each heuristics category (*Rate of Change rule, Age-Illness rule, Pattern rule, Duration rule, Symmetry rule, Optimistic Bias rule, Novelty rule, and Severity rule*) and 'cognitive reasons to consider help-seeking' would discriminate between ambiguous

versus alarm symptoms. For example, if further validation work is being carried out on the PaTH-Q and the study population will focus only on one specific cancer type, for example bowel cancer, it would be valuable to examine the extent to which each heuristics category and 'cognitive reasons to consider help-seeking' will discriminate between ambiguous versus (e.g. unexplained weight loss) and alarm symptoms (e.g. rectal bleeding, abdominal pain, change in bowel habit). It is hypothesised that alarm symptoms have more features that will lead to cognitive triggers to seek help and as such, those individuals who experienced alarm symptoms will have higher heuristics scores and higher scores for 'cognitive reasons to consider help-seeking' compared to individuals who expressed more ambiguous symptoms.

To establish that individuals use heuristics to form a representation about their symptoms as hypothesised in the CSM (Leventhal et al., 1984), the PaTH-Q could be correlated with the IPQ (Weinman et al., 1996). As such it is hypothesised that a high correlation between scores on the PaTH-Q and the IPQ would be an indicator of convergent validity.

Further, another aspect of convergent validity that could be determined is to compare the extent to which each heuristics category and 'cognitive reasons to consider help seeking' is associated with the duration of the appraisal interval and overall TTP. It is hypothesised that for each heuristics category and 'cognitive reasons to consider help-seeking' higher scores will be associated with a shorter appraisal interval and shorter overall TTP. However, given the incomplete information provided by participants on TTP these calculations could not be performed in the current study. In order to minimise the amount of missing data for TTP in future studies, a calendar landmarking technique (Glasner & van der Vaart, 2009) might be used to help/prompt people remember when they noticed symptoms and other dates relating to their diagnosis (Weller et al., 2012). This technique has been used in qualitative studies exploring symptom appraisal and help-seeking behaviour for people recently diagnosed with melanoma and those referred with symptoms suggestive of lung cancer in order to establish the timing and events that led to their diagnosis (Birt et al., 2014; Walter et al., 2014). The authors noted that this approach was helpful, as it enabled participants to refine the time intervals and recall of events alongside their TTP. Similarly, Mills et al. (2014) who examined the use of calendar landmarking instruments in a secondary analysis of 40 patients who had symptoms suggestive of cancer or who had been diagnosed with cancer found that this technique seemed to prompt or help improve recall, particularly when TTP was less than three months.

5.7.3 Conclusions

The PaTH-Q may have an important role to play in future work that aims to assess the contribution of psychosocial factors to symptom appraisal and decision to seek help. Specifically, from the findings obtained so far, it seems that the subscales which show the most promising reliability and validity are *Pattern rule* and *Novelty rule* for the heuristics category, as well as the 'cognitive reasons to consider-seeking help' subscale.

Further analyses (e.g. an EFA followed by a CFA, as well as additional reliability and validity analyses) should be conducted, using a larger sample size, ideally obtained via a clinical setting with patients who have been recently referred with symptoms suggestive of cancer, in order to adequately determine the psychometric properties of the PaTH-Q.

Chapter 6 : General Discussion

6.1 Introduction

The overall aim of this thesis was to develop and validate a new questionnaire, based on the MPT (Scott et al., 2013), that can be applied with patients who have recently sought help for [potential] symptoms of cancer to investigate the psychosocial factors that may impact TTP. To achieve this aim four research studies were carried out. This chapter summarises the main findings of each study and their implications. The methodological strengths and weaknesses of the PhD, implications of findings and areas for future exploration are also discussed.

6.2 Summary of main findings

6.2.1 Measures of psychosocial factors that may influence help-seeking behaviour: a systematic review.

Study One (Chapter Two) was the first systematic review that has aimed to identify how existing studies have measured psychosocial factors affecting actual TTP for [potential] symptoms of cancer.

The systematic search found 36 studies that were identified as suitable for analysis. The vast majority of studies were atheoretical. Only twelve authors noted that their study design was informed by literature reviews and/or theoretical models. It could also not be determined with absolute certainty as to whether the design of new questionnaires was informed by any theoretical models. Furthermore, the majority of studies failed to use valid and reliable tools to measure psychosocial factors which may influence help-seeking behaviour. The relationship between psychosocial factors and TTP is mixed, something that could be attributed to the absence of valid and reliable measures. For instance, only 18% and 22% used valid and reliable to measures to assess 'reasons for delay' and 'symptom interpretation' respectively. This ultimately also impeded conclusions regarding the relationship between psychosocial factors and TTP to be drawn for these studies.

This systematic review set the scene for this PhD thesis and demonstrated that to improve the quality of measurements there is a need for measures that demonstrate both reliability and validity, and whose development is informed by theory.

6.2.2 A secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms and decision to seek help: Applying the Model of Pathways to Treatment.

Study Two which is outlined in Chapter Three, examined whether the qualitative responses given by 49 patients referred with symptoms suspicious of pancreas (n = 8), colorectal (n = 7), oral (n = 8), respiratory (n = 8), melanoma (n = 8), breast (n = 5), and prostate (n = 5) cancer could be classified according to contributing factors specified within the 'appraisal' interval of the MPT (Scott et al., 2013).

Findings from this study revealed that in particular participants used numerous psychological heuristics to form a representation about their symptoms and in turn decide whether symptoms required medical care. There was support for the majority of the heuristics outlined by Scott et al. (2013), namely S*ymmetry rule*, *Rate of Change rule*, *Duration rule*, *Age-Illness rule*, *Optimistic Bias rule*, *Pattern rule*, *Severity rule*, *Novelty rule*, *Location rule* and *Chronology rule*. No support was found for *Prevalence rule* and *Stress-Illness rule*.

Contrary to the CSM (Leventhal et al., 1984), which proposes that bodily changes or symptoms will trigger the formation of illness representations, results revealed that individuals did not appear to specifically form illness representations about cancer. Instead individuals had more generic 'cognitive reasons' that impacted their help-seeking behaviour. Participants' ability to cope (for patients with oral, respiratory, colorectal and pancreatic symptoms) and consequences of symptoms (for patients with pancreatic, respiratory and colorectal symptoms) was also found to be a determinant of their decision to seek medical care. There was little support for emotional response in relation to their symptoms as well as for social factors being seen as a reason to consider seeking help.

The results of this study indicate which contributing factors are most prominent in the accounts of appraisal and helped to identify ways in which each factor is referred to. In particular cognitive heuristics and symptom interpretation appeared key. Doing so ultimately helped to inform the generation of pools of items that reflected the factors of the relevant theory in relation to symptom interpretation.

6.2.3 Development of the Pathways to Healthcare Questionnaire (PaTH-Q: Content and Face Validation

The aim of Study Three (Chapter Four) was to establish content validity (using an expert panel) and face validity (using a patient panel) of a new questionnaire, the PaTH-Q. This determined which elements of the instrument are relevant to and representative of each targeted

construct, and allowed refinement, removal and addition of items prior to final questionnaire preparation and administration. Given the findings from the systematic review and secondary analysis items in the PaTH-Q focused on the heuristics people use to guide symptom interpretation in the 'appraisal' interval of the MPT as well as 'cognitive reasons to consider help-seeking'. Findings from Study One and Study Two helped inform the generation of items in order to create a draft PaTH-Q. Two stages of content and face validation were carried out. The content validity of the PaTH-Q was established using an expert panel (n = 10 in the first round and n = 12 in the second round) consisting of academic researchers, academic general practitioners and experts in the field of questionnaire design. Face validity was determined via cognitive interviews conducted with a sample of n = 8 participants to identify any problems that individuals encounter when they complete the PaTH-Q. Following the first stage of content and face validation modifications were made to the PaTH-Q, specifically Section One and Section Two were combined and problematic items such as reverse worded items were deleted. Content validity of the revised questionnaire, following the second validation stage, was supported by S-CVI/Ave, which ranged from 0.78 to 1.00, and I-CVI, which ranged from 0.70 to 1.00. The majority of items had an item clarity index above 0.78, as well as a scale clarity index above 0.80. Cognitive interviewing indicated that on a whole the PaTH-Q was being interpreted as intended.

6.2.4 Assessment of Psychometric properties

The psychometric properties of the PaTH-Q were determined via a feasibility study. 50 individuals who have previously been diagnosed with cancer were recruited for the purpose of this study and asked to complete the PaTH-Q, as well as the "Symptom Distress Scale" (Meechan et al., 2003), and questions regarding TTP and SES.

The findings from this study indicate that the PaTH-Q has acceptable and good internal consistency for some of the heuristics categories and for 'cognitive reasons to consider help-seeking'. Acceptable levels of internal consistency were found for *Novelty rule* (Cronbach's α = 0.79) and *Pattern rule* (Cronbach's α = 0.74). *Severity rule* demonstrated good internal reliability (Cronbach's α = 0.82). The subscale 'cognitive reasons to consider help-seeking' also demonstrated good internal consistency (Cronbach's α = 0.81). Internal consistency was questionable for the remainder of the subscales.

The PaTH-Q indicated (at least) acceptable convergent validity for *Pattern rule*, *Age-Illness rule*, *Optimistic Bias rule, Rate of Change rule*, *Novelty rule* and *Duration rule* as indicated by the extent to which these subscales were associated with 'cognitive reasons to consider help-

seeking'. Acceptable convergent validity was also found for *Rate of Change rule*, *Pattern rule*, *Age-Illness rule* and 'cognitive reasons to consider help-seeking' as indicated by the extent to which these subscales were associated with 'emotional response to symptom discovery'.

From the findings obtained so far, *Pattern rule* and *Novelty rule*, as well as 'cognitive reasons to consider-seeking help' are the subscales with the most promising reliability and validity.

6.3 Implications of findings

6.3.1 Implications for early diagnosis research

The need for a questionnaire to measure the factors contributing to help-seeking behaviour for [potential] symptoms of cancer became clear from the systematic literature review in Study One. This study found that the majority of existing studies to date have failed to use valid and reliable tools, and which for the most part had inconclusive results regarding psychosocial factors and TTP when no or minimal psychometric evidence was present. Ultimately, the findings from this systematic review echo calls by numerous authors about the need for robust and reliable measures (Andersen et al., 2009; Weller et al., 2012; Scott & Walter, 2010; Scott et al., 2013). Although the term 'patient delay' was first coined by Pack and Gallo (1938) nearly 80 years ago and researchers have attempted to measure patient factors influencing delay in seeking help for symptoms of cancer for almost as long, it appears that when it comes to determining the contributing factors associated with TTP, with the help of reliable and valid measures, based on (a) theoretical model(s), the area is still in its infancy.

Secondary analyses (Chapter Three) supported the existence of the appraisal interval and that existing theory such as the CSM can be used to help explain contributing factors in the appraisal interval as hypothesised in the MPT (Scott et al., 2013). For example, Birt et al. (2014) who used a framework analysis underpinned by the MPT found that individuals used numerous coping procedures to deal with their symptoms. People often self-managed symptoms to contain illness; some monitored their symptoms to see if they were changing before help-seeking was instigated or they decided to re-appraise their symptoms, especially if symptoms changed or if the medication for their prescribed treatment failed to alleviate symptoms. Findings from the secondary analysis (Chapter Three) also showed that the appraisal interval was primarily influenced by psychological heuristics on which there has been a lack of research thus far. Furthermore, findings from recent studies show support for the existence of some heuristics in studies that have examined contributing factors for help-seeking. For instance, a study that aimed to explore how the interpretation and response to

breast cancer symptoms in women from different SES groups could be understood by theoretical models within the MPT, such as the CSM, found that women frequently attributed symptoms to benign causes, such as age or menopause (Marcu et al., 2016). This finding is in line with the *Age-Illness rule.* Similarly, even though this study or its analysis was not informed by the MPT, Whitaker, Macleod, Winstanley, Scott, and Wardle (2015) noted that symptoms were attributed to normal processes, such as getting older (in a study that explored people's decision to seek help for cancer alarm symptoms). There is also support for other heuristics, such as the *Chronology rule.* Results by Birt et al. (2014) indicated that people often had alternative explanations for respiratory symptoms and frequently explained symptoms as a response to specific activities, muscle spasm was attributed to gardening, whereas breathlessness was seen as arising from exertion. Moreover, support for heuristics was also evident in findings by Evans, Chapple, Salisbury, Corrie, and Ziebland (2014) who categorised data according to the appraisal interval of the MPT in a study that examined how people with pancreatic cancer interpreted symptoms, and what triggered them to seek help for intermittent symptoms. Results revealed that help was frequently sought if symptoms changed, became more frequent or increased in number (*Rate of Change rule*) or were persistent (*Duration rule*).

The systematic review (Chapter Two) indicated that the majority of existing studies have predominantly measured how symptom interpretation, reasons for delay, emotional response or social factors have affected TTP for [potential] symptoms of cancer. Whilst it is of course acknowledged that all these elements may be important in the pathway to diagnosis, the secondary analysis in Chapter Three revealed that there might indeed be other factors that drive the appraisal of symptoms and thus the help seeking process. This notion was also raised by de Nooijer, Lechner and de Vries (2003) who suggested that the factors which drive the detection and interpretation of symptoms may indeed be different to the ones that drive the help-seeking process.

Study One and Study Two also underline the importance of using theoretical models when designing studies or measures as suggested by Scott and Walter (2010) who noted that a vast list of factors does not enable researchers to precisely pinpoint how and which factors have an effect, where in the TTP pathway factors have an effect or whether some factors have more effects than others. Nevertheless, if the appraisal interval influences subsequent help-seeking behaviour, it is of course imperative to adequately and systematically establish which factors determine symptom appraisal. Doing so is also important, especially if researchers also wish to develop effective interventions to promote the early diagnosis of cancer given that many

interventions to date, such as the 'Be Clear on Cancer' campaigns (Department of Health, 2011) highlighted in Chapter One, have failed to result in a significant increase in referrals over a prolonged period or in more cancers being diagnosed.

6.3.2 Implications for questionnaire development

Design and validation of the questionnaire was accomplished by adhering to recommendations about basic concepts of questionnaire development. In Study One (Chapter Two) a systematic review was carried out to identify how existing studies have measured psychosocial factors affecting actual TTP for [potential] symptoms of cancer. The need to be aware of any potential suitable measures was endorsed by Streiner et al. (2015) who criticised researchers for frequently dismissing existing scales without giving them sufficient consideration, and instead opting to develop a new measure. However, as indicated by the findings, few reliable measures exist in this field overall and there are also currently no measures that measure heuristics or 'cognitive reasons to consider help-seeking'. For example, even though the systematic review (Chapter Two) revealed that there are measures that focus on symptom interpretation; measures that have measured symptom interpretation thus far have predominantly asked questions pertaining to the attributions and cause of symptoms, or whether symptoms were perceived as serious. As such, it can be argued that they fail to capture the full range of cognitive reasons to seek help or the cognitive processes involved in symptom interpretation. Furthermore, although fourteen studies examined symptom interpretation only two studies used a measure with some evidence of either reliability or validity (O'Mahony et al., 2013; Unger-Saldana et al., 2012). O'Mahony et al. (2013) studied symptom interpretation at the point of seeking help, rather than at the point of appraisal of symptoms and Unger-Saldana et al. (2012) only focused on perceived seriousness of symptoms (and this questionnaire was tested in Spanish only).

Study Three (Chapter Four) highlighted the importance of establishing content and face validity as it enabled extensive changes to be made to the PaTH-Q, such as combining Section One and Two, in addition to items being added and/or removed prior to assessing the feasibility of the PaTH-Q in Study Four (Chapter Five). Even though the psychometric properties of the PaTH-Q could not be fully established and findings need to be interpreted with caution due to the small sample size, and further validation studies need to be conducted in order to establish the psychometric properties of the questionnaire, it is hoped that if implemented in future research studies the PaTH-Q will enable researches to effectively

determine the contribution of psychosocial factors to symptom appraisal and the decision to seek help.

6.3.3 Methodological Limitations

The limitations of the studies were discussed in each chapter. However, the following section will highlight and discuss broad methodological issues that are relevant to this thesis.

6.3.4 Study sample and potential for bias

In order to establish face validity, participants were recruited from PPI groups. Members of PPI groups may be particularly interested in taking part in research studies given that PPI groups aim to advance research by ensuring that it is relevant to the patient and making a difference to the patient experience (A Strategy for PPI in Cancer Research in Northern Ireland, 2011). Nevertheless, while the usage of PPI groups is beneficial to this study, because the questionnaire should be validated with the target population in mind (Bryman, 2006), this strategy may also pose implications for response bias. As outlined in the discussion of Chapter Four, the researcher's presence during the 'think aloud' task might have introduced social desirability bias even though the researcher sat out of sight. The occurrence of social desirability bias may have also been the case in Study Four. It is likely that individuals who were recruited for Study Four (Chapter Five) were also more motivated to take part in research concerning cancer. Participants were recruited from cancer charities that provide patient involvement opportunities for individuals affected by cancer. These opportunities enable individual to share their experiences of diagnosis, treatment and care by getting involved in research, for example. Further, the researcher received many emails where interested participants said that they were keen to take part in the study as they would like to give something back.

Finally, the experts involved in determining content validity were selected from a fairly small field. It would have been helpful to include more experts whose expertise is in psychometrics and/or questionnaire design as these experts may have been able to raise further potential flaws pertaining to content validity, and therefore avoid any future reliability or validity problems that might arise due to poor item design.

6.3.5 Alternative Methodology

6.3.5.1 Consultation with experts

It could have been beneficial to conduct a Delphi Method study prior to designing items for the PaTH-Q as this would have highlighted conceptual issues related to the definitions of heuristics. In the Delphi method a questionnaire focusing on the specified problem is developed and sent to an expert panel. After all the questionnaires have been returned to the researcher the responses from the first round are analysed and ranked using a set of prearranged criteria. A second questionnaire and a feedback summary based on the results and feedback is designed and sent to the experts. After experts have reviewed the feedback summary they are asked to rate the priority areas in the second questionnaire. This process is repeated until a consensus has been reached (Hasson, Keeney, & McKenna, 2000). As documented in Chapter Three, relatively few studies exist that have investigated how individuals use heuristics to form a representation about symptoms and decide whether their symptoms warrant medical care. Although a categorisation matrix was used to help code the data, whilst doing so it became apparent that there were problems with some of the definitions for heuristics influencing the interpretation of symptoms as outlined by Scott et al. (2013). Thus, some of the definitions were modified. Even though heuristics were clarified by the researcher and her supervisors it would have been beneficial to get further expert opinion, as this would have eliminated any bias arising as a result of subjective interpretation. Moreover, responses from the expert panel study indicated that there was one expert who noted that they did not understand the heuristic or that the heuristic needed further clarification.

6.3.5.2 Consultation with respondents

Although the think 'think-aloud' method is the preferred method used to establish face validity and although this method was beneficial to the development and revision of the PaTH-Q, it could be argued that verbal probing might have indicated further issues with the questionnaires. Many participants might not have highlighted weakness associated with the questionnaire (e.g. inadequate response options, questionnaire layout, etc.), because they were not asked to do so. Willis et al. (1991) has questioned whether think-aloud responses are useful for assessing other questionnaire issues, and suggested that it may be more straightforward to probe directly about such matters.

6.3.6 Primary versus secondary analysis of data

One issue that arose during the secondary analysis of qualitative data (Chapter Three) was the problem of not having been there during the data collection phase. As such, the researcher analysed data that were collected by other researchers which at times made immersion with the data difficult and could have led to misinterpretation, ultimately resulting in bias. It is, however, believed that these effects should have been reduced as one transcript from each cancer type was read and coded by SS and FW. Coding by SS and FW was then compared with the coding by SK. If any discrepancies in coding arose they were discussed until agreement was reached. Furthermore, SS double checked the excerpts/quotations from the heuristics category to ensure that they were coded under the correct category.

An alternative to the secondary qualitative analysis would have been to conduct a new qualitative study. However, designing and performing a new qualitative study would be somewhat obsolete as 1) sufficient data were available from existing studies, and 2) the questions which would have been asked in the interview would have been similar to the ones that were asked in the existing studies. Therefore, performing a secondary analysis ultimately meant that time and resources could be spent on developing and validating the PaTH-Q across a number of cancer types and countries.

6.4 Directions for future research

6.4.1 Future research on Heuristics

Through the findings from the study it became apparent that there is scope for further conceptual work surrounding heuristics involved in symptom interpretation. It could be argued that the heuristics refer to different aspects of symptom interpretation and help-seeking. For example, some refer vaguely to noticing symptoms (e.g. *Location rule* and *Similarity rule*), some refer to seriousness of symptoms (e.g. *Duration rule*), and some refer to motivation to seek help (e.g. *Novelty rule*). Thus people may be using different heuristics for different purposes. As a result of this, the current definitions could be further improved by developing a typology of heuristics and translating these into more specific theories of the factors that influence different aspects of symptom interpretation and help-seeking.

There is also no information currently available about which heuristics are most influential in the decision as to whether symptoms require medical care. Although, findings from the secondary analysis (Chapter Three) revealed that the *Rate of Change rule* was the most

prominent heuristic it is currently not known whether it was this most commonly cited rule that motivated individuals to seek help.

We also do not currently know whether heuristics occur in a sequential order or if/how they work in combination. For instance, *Symmetry rule* could occur first, followed by *Rate of Change rule* and so forth. Further analyses of the transcripts to see whether individuals refer to certain heuristics first might shed further light on this.

Analyses of routinely recorded data in England has shown that lower SES, male sex and older age were risk factors for later stage at diagnosis across seven common cancers, and it was predicted that if sociodemographic inequalities were eliminated this would result in 5 600 fewer patients a year being diagnosed at an advanced stage in England, ultimately leading to a considerable increase in cancer survival rates (Lyratzopoulos et al, 2013). Therefore the usage of heuristics could also vary amongst people from different SES backgrounds. Future studies could establish any variation in the usage of heuristics in individuals from different SES backgrounds, ethnicity and education.

Even though 49 interviews were analysed in total for the secondary analysis, when each individual cancer type is taken into account this number is quite small. As such, quantitative methods are necessary to compare data in a systematic way, make generalisations to the whole population or test theories with hypothesis. Given that the sample size in Study Four (Chapter Five) only consisted of 50 individuals it was not possible to compare responses between people with different cancer types or symptoms. Again, this would be an important avenue for future research.

6.4.2 Future research on the Pathways to Healthcare Questionnaire (PaTH-Q)

While the intention of Chapter Five was to assess the psychometric properties of the questionnaire, the small sample size severely restricted this aim. Even though the findings from this study indicated that the PaTH-Q shows promising reliability and validity for some of the subscales (*Pattern rule* and *Novelty rule*, as well as 'cognitive reasons to consider help-seeking') the small sample size severely inhibits the confidence with which conclusions regarding the reliability and validity can be made due to potential bias. Consequently, before the PaTH-Q is used in any future research studies an important first step is to conduct another feasibility study, preferably with patients who have recently sought help for potential symptoms of cancer in order to examine the psychometric properties at the scale and item

level by analysing unidimensionality via an EFA (followed by a CFA), internal consistency, item discrimination, predictive, discriminant and construct validity.

Once reliability and validity is established, a large scale quantitative study will be required in order to determine the relative importance of each heuristic towards TTP.

Even though the PaTH-Q was developed in order to be used in a cancer population, once its psychometric properties have been adequately established, the PaTH-Q could be used in other populations for which a delay in help-seeking has been found, such as sexual transmitted diseases (e.g. Malek, Chang, Clark, & Cook, 2013; Meyer-Weitz, Reddy, Van den Borne, Kok, & Pietersen, 2000) or mental health (e.g. Eisenberg, Downs, Golberstein, & Zivin, 2009; Mackenzie, Gekoski, & Knox, 2006; Rickwood, Deane, Wilson, & Ciarrochi, 2005), in order to determine the contribution of psychosocial factors of symptom appraisal and decision to seek help. Moreover, it would be useful to test the PaTH-Q in illnesses beyond cancer to further establish its reliability and validity. However, when doing so it should be noted that establishing reliability and validity is an ongoing process; if a validated measure is to be used with a different population and/or under different circumstances the findings from the initial validation study may no longer be applicable and the instrument should be validated again (Streiner et al., 2015).

Given that items in the PaTH-Q do not prelude a stem that taps into the perceived need for help-seeking (as Version Three did for example); the PaTH-Q could also be adapted for use in prospective studies that measure hypothetical help-seeking behaviour or used in longitudinal studies. These studies would also enable the predictive validity of the PaTH-Q to be established.

Whilst items in the PaTH-Q have been designed following the support found for heuristics and 'cognitive reasons to consider help-seeking' in the appraisal interval, it is acknowledged that the PaTH-Q does not cover all the elements in the CSM that can be used to explain the contributing factors in the appraisal interval. Specifically, it does not focus on emotions, coping procedures and the full range of reasons to consider help-seeking. Nevertheless, there are valid and reliable measures for emotions and coping (as outlined in Chapter three) that could be used in conjunction with the PaTH-Q, should the PaTH-Q prove to be reliable and valid and could hence be used in future studies.

6.4.3 Future research on the help-seeking interval

This thesis only examined the extent to which the CSM (Leventhal et al., 1984) can help to further explain processes in the appraisal interval. Further research is therefore necessary to establish the existence and relative contribution to which the SCT (Bandura, 1986; 1997) can explain an individual's decision to seek help after perceiving a reason to discuss a symptom with a HCP as hypothesised in the MPT (Scott et al., 2013).

Given the absence of valid and reliable tools used to determine reasons for delay (see Chapter Two), with which the PaTH-Q could potentially be combined in order to determine the contributing factors in both the appraisal and help-seeking interval, other valid and reliable measures may need to be adapted from those currently used to determine the barriers to hypothetical help-seeking. For example, the Cancer Awareness Measure (CAM; Stubbings et al., 2009) and the Awareness and Beliefs about Cancer tool (ABC; Simon et al., 2012) are tools that have been used in a range of studies examining hypothetical help-seeking (e.g. Forbes et al., 2013; Quaife et al., 2014) and more recently in patients with cancer (Forbes et al., 2014). However, regarding the ABC tool, even though factor analysis results and stability analyses across countries showed that the latent variable was well defined, Cronbach's α for the aggregate score for the subscale measuring beliefs about barriers to symptomatic presentation was low (0.52). Thus more developmental work may be needed on this scale. Nevertheless, it could be argued that until a more psychometrically sound measure has been established, the CAM and ABC tool could be adapted, as an initial step, to determine barriers to actual help-seeking behaviour and used in combination with the Path-Q.

6.5 Final Conclusions

Prior to starting this thesis a measure that examines the heuristics involved in symptom interpretation and 'cognitive reasons to consider help-seeking' did not exist. Researchers thus far have never measured the existence of heuristics in a quantitative manner perhaps due to the lack of information on how to operationalise these theoretical constructs. This PhD thesis identified a need for a measure that focuses on heuristics and 'cognitive reasons to consider help-seeking', which ultimately led to the development of the PaTH-Q. This thesis has begun the process of reliability and validity testing, and has found that the PaTH-Q demonstrates good content and face validity, and shows promising internal consistency and convergent validity for some heuristics, even though the latter findings may be subject to bias given the study's small sample size and should therefore be interpreted with caution. As such, work remains to be done to fully determine the psychometric properties of the PaTH-Q.

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PhD related publications and presentations

Journal Papers

Kummer, S., Walter, F. M., Chilcot, J., & Scott, S. (Accepted for publication; in press). Measures of psychosocial factors that may influence help-seeking behaviour in cancer: A systematic review of psychometric properties. *Journal of Health Psychology*.

Kummer, S., Walter, F. M., Chilcot, J., Sutton, S., Emery, J., & Scott, S. (Manuscript in preparation). Evidence of cognitive heuristics underpinning symptom appraisal for symptoms of seven cancers: a secondary qualitative analysis.

Conference Presentations

Kummer, S., Walter, F. M., Chilcot, J., & Scott, S. (2017). *Development of the Pathways To Healthcare Questionnaire (PaTH-Q): Content and Face Validation.* E-Poster presented at the Ca-PRI Network Meeting, Edinburgh, UK.

Kummer, S., Walter, F. M., Chilcot, J., & Scott, S. (2016). *A secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms and decision to seek help: Applying the Model of Pathways to Treatment.* Oral presentation given at the Ca-PRI Network Meeting, Boston, USA.

Kummer, S., Walter, F. M., Chilcot, J., & Scott, S. (2015). *How are psychosocial factors that may influence help-seeking behaviour measured? A review*. Poster presented at the British Psychological Society, DHP Annual Conference, London, UK.

Kummer, S., Walter, F. M., Chilcot, J., & Scott, S. (2015). *How are psychosocial factors that may influence help-seeking behaviour measured? A review*. Poster presented at the APOS World Congress, Washington D.C., USA.

Kummer, S., Walter, F. M., & Scott, S. (2014). *A secondary qualitative analysis of the factors that contribute to patients' appraisal of symptoms and decision to seek help: Applying the Model of Pathways to Treatment.* Poster presented at the British Psychological Society, DHP Annual Conference, York, UK.

Appendices

Appendix 1: Pre-publication proof of Systematic Review (Study One)

Journal of Health Psychology

Journal of Health Psychology

Measures of psychosocial factors that may influence help-seeking behaviour in cancer: A systematic review of psychometric properties.

Journal:	Journal of Health Psychology
Manuscript ID	JHP-16-0325.R3
Manuscript Type:	Review Article
Keywords:	CANCER, MEASUREMENT, HELP-SEEKING, SYMPTOMS, SYSTEMATIC REVIEW

Abstract:	Advanced stage cancer is frequently attributed to delays in presentation to a healthcare professional. To reduce undue delay, it is imperative to understand the reasons underlying help-seeking behaviour and to measure those using valid and reliable tools. This systematic review aimed to identify how studies have measured psychosocial factors affecting time to presentation for potential cancer symptoms. 35 studies were included. Most studies failed to use valid and reliable tools, and predominantly provided inconclusive results regarding psychosocial factors and time to presentation when no or minimal psychometric evidence was present. Consequently, measure selection and future measure development should be guided by psychometric principles.

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Advanced stage cancer is frequently attributed to delays in presentation to a healthcare professional. To reduce undue delay, it is imperative to understand the reasons underlying help-seeking behaviour and to measure those using valid and reliable tools. This systematic review aimed to identify how studies have measured psychosocial factors affecting time to presentation for [potential] cancer symptoms. 35 studies were included. Most studies failed to use valid and reliable tools, and predominantly provided inconclusive results regarding psychosocial factors and time to presentation when no or minimal psychometric evidence was present. Consequently, measure selection and future measure development should be guided by psychometric principles.

Keywords

Cancer; measurement; help-seeking; symptoms; systematic review;

Introduction

Advanced stage cancer at diagnosis is frequently attributed to delays occurring at various stages during the diagnostic process (Richards, 2009). This paper focuses on the time to presentation (TTP; the period of time between an individual's first detection of a bodily change and the first consultation with a healthcare professional) for symptomatic cancer (as opposed to screen-detected cancer). If timely symptomatic presentation is to be achieved it is important to understand the influences on help-seeking behaviour (Walter et al., 2012).

The influence of psychosocial factors to TTP

Numerous studies have concluded that TTP may be influenced by a range of psychosocial factors. However, five systematic reviews that examined help-seeking for symptoms of cancer have yielded mixed findings concerning which psychosocial factors influence TTP and whether they increase or decrease TTP (Macdonald et al., 2006, Macdonald et al., 2004, Mitchell et al., 2007, Ramirez et al., 1999, Richards et al., 1999). For example, the studies included in these reviews revealed that symptom awareness was associated with shorter TTP in three studies (Delaney, 1998, Gullo et al., 2001, Ojala et al., 1982) and longer TTP in six studies (Arvanitakis et al., 1992, Ibingira, 2001, Mikulin and Hardcastle, 1987, Nagao and Takahashi, 1979, Porta et al., 1996, Rothwell et al., 1997) for individuals with upper gastrointestinal (GI) cancer. Another psychosocial factor which has shown to have an inconclusive impact on TTP are social networks. In lower GI cancer, social networks were identified to reduce TTP in five studies (Camilleri-Brennan and Steele, 1999, Holliday and Hardcastle, 1979, MacArthur and Smith, 1984, Roncoroni et al., 1999, Sladden et al., 1999), whereas it was not regarded as important in two studies (Macadam, 1979, Samet et al., 1988). Similar findings concerning the impact of emotions have been found by Balasooriya-Smeekens et al. (2015) who noted that the impact of emotions on TTP was mixed. It is hypothesised that mixed findings may have occurred because different studies have used

different ways of defining and measuring psychosocial factors, including the use of measures without proven reliability or validity.

Although there has recently been a focus on the design and validation of measures examining factors influencing hypothetical help-seeking behaviour (e.g. Simon et al., 2012, Stubbings et al., 2009) there is sparse information about whether quantitative measures of psychosocial factors affecting TTP are reliable or valid. This makes it difficult to guide the selection of measures to robustly assess the key decisional and behavioural processes that affect the pathways to healthcare use or select measures for use in the evaluation of interventions aiming to promote timely presentation (Scott et al., 2013). One recommendation in the Aarhus Statement (guidelines for improvement in methodological approaches in early diagnosis research; Weller et al., 2012) was the need for use of valid and reliable measures. Numerous problems might arise if measures are not valid. For example, Haynes et al. (1995) argue that a measure which fails to demonstrate adequate content validity can under or over represent as well as oversee aspects that are not a part of the construct domain. A measure which adequately comprises all aspects of the intended outcome variables enables more precise assumptions. Also, measures which have shown to have a high content validity offer wider conclusions to be drawn about individuals in a range of settings and circumstances. The importance of construct validation should also not be over looked. It can be argued that in help-seeking research the absence of a theoretically chosen defined set of construct has led to psychosocial factors being chosen unsystematically. This is problematic because it results in a large list of factors impossible to measure in a single study (Scott and Walter, 2010). Several authors have also commented on the lack of theoretical frameworks used to underpin the patient pathway to symptom interpretation and diagnosis (Weller et al., 2012, Walter et al., 2012, Andersen et al., 2009, Scott and Walter, 2010). Without theoretical underpinning researchers are unable to adequately determine which factors are most important, how and

when in the diagnostic pathway factors have an effect, or if some factors have more than one effect (Scott and Walter, 2010).

Indicators of a robust measure

Reliability can be established via internal reliability which "is the extent to which items in a questionnaire (sub)scale are correlated (homogeneous), thus measuring the same concept." (Terwee et al., 2007, p.36). Given that internal consistency reliability is unable to capture whether an instrument is reproducible over time it has been suggested that other measures of reliability such as intra-observer, inter-observer or test-retest reliability should be established and/or considered (Streiner et al., 2015). Using measurements that only demonstrate reliability is not sufficient, because a measure may be reliable but not valid. Consequently, validity needs to be established to ensure that a measurement measures what it intends to measure (DeVellis, 2011). DeVellis (2011) notes that there are three main types of validity: content validity (degree to which the measure covers all the constructs of interest), criterion validity (degree to which a measure is related to other measures that examine the same construct) and construct validity (degree to which a measurement captures a specific trait or theoretical construct and thus relates to measures of different constructs). According to Lynn (1986) content validation is comprised of two stages: development and judgment quantification. The development stage consists of classifying the content domain (for example via a literature review), generating items, and constructing the measure. Judgment quantification, on the other hand is obtained via an expert panel who are asked to evaluate whether potential items fit the content domain. Content validity can be quantified by calculating a content validity index (CVI), with a CVI of .80 indicating a good agreement between raters (Lynn, 1986). Assessments of content validity can also involve investigating face validity, which is the subjective judgement (usually by users) of the measurement as to whether it appears to measure what it is supposed to. Assessments of face validity sometimes

also cover the interpretability, usability and appearance of the questionnaire. For an instrument to be construct valid, both convergent (two measures that assess theoretically related constructs should correlate with each other) and discriminant validity (two measures that assess a dissimilar construct should not correlate with each other) should be established; only one of these is not sufficient enough to establish construct validity (Trochim, 2006).

Purpose of this review

The primary aim of this systematic review is to investigate the psychometric properties of current measures used to assess psychosocial factors affecting TTP. The secondary aim is to use this information to assess whether using a robust measure (rather than one with no proven validity or reliability) results in different reported predictors of TTP. Doing so will serve two functions: 1) to help researchers choose suitable measures and 2) to identify areas in which new psychometrically robust measures are needed.

Methods

Two approaches were used. Firstly, reference lists of five existing systematic reviews (Macdonald et al., 2006, Macdonald et al., 2004, Mitchell et al., 2007, Ramirez et al., 1999, Richards et al., 1999) were searched. These reviews focused on patient factors in help-seeking for symptoms of cancer, and documented a comprehensive review of the world literature from the pre 1970s to November 2003 and encompassed a range of cancers. Secondly, a systematic literature search was conducted to identify studies that were published since the most recent systematic review (Mitchell et al., 2007). We systematically searched Medline, EMBASE, CINAHL, PSycINFO and Web of Science to include papers published between January 2004 to May 2014.

Search terms focused on four main themes: psychosocial factors, help-seeking, cancer and symptoms (see Supplementary Data File 1, Table 1). Given the large number of possible

psychosocial factors, we defined psychosocial factors as "psychosocial factors, including emotional, cognitive, and behavioural responses of the patient to the discovery of a breast symptom, and social influences, psychiatric history, and previous medical help-seeking" (adapted from Ramirez et al.'s (1999) classification of psychosocial factors (p. 1128)).

We included original research papers published in peer-reviewed journals, which examined psychosocial factors in relation to symptom appraisal or help-seeking for symptoms of cancer (all types) or symptoms potentially indicative of cancer. Papers were included if the study 1) measured actual TTP (or sub-components such as the appraisal interval and help-seeking interval) for [potential] symptoms of cancer, 2) examined contributing psychosocial factors to determine their effect on actual TTP for [potential] symptoms of cancer and 3) collected data through quantitative primary research. Qualitative studies, even when data was later quantified, were excluded because our aim was to examine how psychosocial factors influencing TTP have been measured in a quantitative manner (and thus could be replicated in future studies). Manuscripts were also excluded if they were reporting presentations at conferences, focused on screening or were set among non-symptomatic individuals.

Two reviewers independently extracted data from all papers identified as potentially relevant for inclusion. Extracted data included study and participant characteristics, and measurement characteristics, specifically 1) which psychosocial factors were assessed, 2) how psychosocial factors were measured, 3) items/questions used, 4) details on validity and reliability, and 5) the relationship between each psychosocial variable and TTP (when inferential statistics had been used). Any disagreements were resolved by a third reviewer.

A descriptive, narrative approach to synthesise the papers was chosen because we aimed to compare and contrast measurement information across the included studies rather

than the results of the studies. We did not exclude any studies based on their quality because we wanted to demonstrate the quality of existing measures as part of this review.

Results

From the initial 20 953 references identified via the systematic search, 35 papers were included in the review (see Supplemental Data File 2, PRISMA flow diagram).

Study and Participants Characteristics

Details of the 35 included papers can be found in Supplementary Data File 4, Table 1. The sample size of the studies ranged from 37 (Bowen and Rayner, 2002, Cochran et al., 1986) to 1085 (Courtney et al., 2012) participants. Age ranged from 31 years (Bosl et al., 1981) to 89 years (Prohaska et al., 1990). The majority of studies were set in the USA (n = 10) and the United Kingdom (n = 6). Nine studies reported data from various types of skin cancer, eight studies were conducted with individuals with breast cancer, four studies investigated colorectal cancer, whereas five studies looked at oral cancer or head and neck cancer. The remaining studies investigated endometrial, lung, bladder, germ cell testicular or penile cancer. One study (Risberg et al., 1996) reported findings from a variety of cancer types and one study investigated a range of gynaecological malignancies (Andersen et al., 1995).

Measurement of Psychosocial Factors

Psychosocial factors were primarily measured via self-administered questionnaires or interviewer administered questionnaires. One study used medical records (Bosl et al., 1981), whereas another used a combination of structured interviews and questionnaires (Cochran et al., 1986). The 35 papers documented 101 measures in total, the vast majority of which (80%; n = 81) were newly developed for that study, whereas 20 used existing scales (15 of which were modified for the study). In the instances where existing scales were used, most

(95%; n = 19) had some evidence of reliability (mainly internal reliability) or validity or both. The new measures rarely documented psychometric properties: 7% (n = 5) demonstrated internal reliability; 11% (n = 9) demonstrated test-retest reliability; 15% (n = 12) demonstrated face validity; 12% (n = 10) demonstrated content validity; 4% (n = 3) demonstrated construct validity; none of the new measures were tested for criterion validity (see Table 1).

Twelve studies (Kumar et al., 2001, Reifenstein, 2007, O'Mahony et al. 2013, Andersen et al., 1995, Friedman et al., 2006, Li et al., 2012, Ristvedt and Trinkaus, 2005 Hashim et al., 2010, O'Mahony and Hegarty, 2009, Reifenstein, 2007, Unger Saldana et al., 2012, Scott et al., 2008) stated that theoretical models and/or literature reviews were used to inform the study design, but it was not always clear as to whether theoretical models were used in the design of new questionnaires.

*** Insert Table 1 here ***

Nine broad categories of psychosocial factors were measured by the reviewed studies. These are outlined below with measures showing evidence of reliability and validity discussed in more detail. The findings of the studies (focusing on the relationship between each psychosocial factor and TTP) are presented in relation to the studies' reported psychometric properties (see Table 1).

Reasons for delay

i) Robustness of measures

Seventeen studies explored 'reasons for delay' in seeking help. Three studies (Reifenstein, 2007, Scott et al., 2008, Unger Saldana et al., 2012) used a scale with some

evidence of reliability or validity.

Reifenstein (2007) used an adapted 12 item version (Lauver, 1994) of 'Melnyk's Barrier Scale' (Melnyk, 1990) to assess barriers. Internal consistency for the scale was reported as Cronbach's α = .73 in Reifenstein's study (2007) and Cronbach's α = .70 in a study conducted by Lauver (1994).

Unger Saldana et al. (2012) examined 'patient's perceived reason for patient delay' by assessing a range of factors such as lack of financial resources, embarrassment or difficulty to miss work. Internal consistency for this dimension was reported as good, with Cronbach's α = .85. The specific test-retest correlation for this specific scale was not indicated, but the authors noted that test-retest correlations ranged from poor (r <.4) to good (r >.75) for the whole questionnaire. Tests of convergent validity showed that items within this dimension correlated with each other (r = .2 to r = .64). Items belonging to different dimensions were either poorly or not correlated with each other, therefore indicating divergent validity. Face and content validity of the entire questionnaire was investigated in the questionnaire development process using evaluation from a multidisciplinary team.

Scott et al. (2008) determined the presence of competing events in participants' lives using a modified version of the 'Social Readjustment Scale' (Holmes and Rahe, 1967). No details on reliability or validity were reported by Scott et al. (2008), but Gerst et al. (1978) had previously examined the reliability of the 'Social Readjustment Scale' in groups of psychiatric outpatients and non-patients (male employees at a hospital and university campus) during three sampling periods over two years, finding that total rank ordering remained consistent for psychiatric outpatients (r = .91 to r = .70) and non-patients (r = .96 to r = .89) over the sampling periods.

ii) Relationship with TTP

'Reasons for delay' were generally associated with longer TTP (Friedman et al., 2006, Kakagia et al., 2013, Li et al., 2012, O'Mahony and Hegarty, 2009, Scott et al., 2008). However, not all measured barriers were found to be associated with longer TTP. For example, findings by Friedman et al. (2006), whose barrier items identified 'cancer worry', 'appointment trouble', 'cost', 'treatment worry', 'fear of breast loss', 'can't get off work and 'rather not think about it', showed that only being more likely to identify cost was associated with longer TTP. Findings, by Kakagia et al. (2013) showed that all the variables other than 'fear of diagnosis' were associated with longer TTP. For one study (Prohaska et al., 1990) only one out of eight barriers was associated with shorter TTP. There was no significant relationship between 'reasons for delay' and TTP in three studies (Friedman et al., 2006, Reifenstein, 2007, Smith and Anderson, 1987). None of these studies used measures with evidence of validity and only two studies showed evidence of reliability (Reifenstein, 2007, Scott et al., 2008).

Reasons for seeking help

i) Robustness of measures

Six studies investigated 'reasons for seeking help'. Two of these studies (Reifenstein, 2007, Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Unger-Saldana et al. (2012) measured 'patient's reason for seeking medical care' by assessing numerous factors such as appearance of symptoms, persistence of symptoms and worsening of symptoms. Face and content validity of the entire questionnaire was determined in the questionnaire development process.

Utility was measured by Reifenstein (2007) via 13 outcome statements originally developed by Lauver (1992a). A utility score was calculated based on expectations and

values of outcomes of help seeking. In Lauver's study (1992a) test-retest correlation for the average expectation score was r = .71 and Cronbach's alpha was α = .71 and α = .78 on two administrations. Test-retest correlation for the average value score was noted as r = .54 and Cronbach's alpha was α = .68 and α =.73 on two administrations. In Reifenstein's (2007) study, Cronbach's alpha was α = .97 for the value outcomes. Reifenstein (2007) did not provide any details on the reliability for the expectations outcome.

ii) Relationship with TTP

'Reasons for help-seeking' were associated with shorter TTP in one study (O'Mahony and Hegarty, 2009). Two studies showed no significant relationship between 'reasons for seeking help' and TTP (Brochez et al., 2001, Reifenstein, 2007). Only one study used a scale with some evidence of reliability or validity (Reifenstein, 2007).

Knowledge

i) Robustness of measures

Eight studies investigated how 'knowledge' affected TTP. Three of these studies (Kumar et al., 2001, O'Mahony et al., 2013, Scott et al., 2008) used a scale with some evidence of reliability or validity.

Kumar et al. (2001) examined whether cancer can develop if tobacco is used as part of a 60 item questionnaire. Test-retest reliability of the whole questionnaire was examined in a sample of 10 participants over seven days. The reliability of the final questionnaire was acceptable (ICC = .81).

O'Mahony et al. (2013)[1] examined women's breast cancer knowledge using a 15 item modified version of the 'Breast Cancer Knowledge Scale' (Facione et al., 2002). The original version of the scale (Facione et al., 2002) has shown good internal consistency (α = .88). Content and face validity in O'Mahony's (2013)[1] study were determined by an expert panel

of clinical and research experts. Content validity was further confirmed by ensuring that participants' breast changes reflected the breast changes outlined in the literature. O'Mahony et al. (2013)[1] reported the average content validity index for the scale as .85.

Scott et al. (2008) examined knowledge and beliefs about oral cancer via the 36-item 'Knowledge and beliefs about oral cancer' questionnaire (Humphris et al., 1999). No details on reliability or validity were reported by Scott et al. (2008), but in the original study the questionnaire showed an acceptable reliability with KR-20 reported as .76 (Humphris et al., 1999). Humphris et al. (1999) determined criterion validity by the scale's ability to differentiate between four different groups of respondents ($F = 12.41$; $df = 3,143$; $p < .0001$).

ii) Relationship with TTP

Two studies with some evidence of reliability and validity found higher knowledge to be associated with shorter TTP (Scott et al., 2008; O'Mahony et al., 2013). Studies with limited or no evidence of reliability or validity reported mixed results, with no link between knowledge and TTP in a study by Kumar et al. (2001) and Oliveria et al. (1999) (knowledge of bleeding and scab not healing as a sign of skin cancer); knowledge of general oral health being linked to shorter TTP (Panzarella et al., 2014) or that compared to no knowledge, knowing quite a lot was linked to longer TTP (Smith et al., 2009).

Perceived Risk

i) Robustness of measures

Three studies investigated how 'perceived risk' affected TTP (Friedman et al., 2006, O'Mahony and Hegarty, 2009, Smith et al., 2009) using newly developed measures. None of the authors stated whether any psychometric testing procedures were carried out in order to assess reliability or validity.

[1] Further information about measurement details obtained from O'Mahony (2011).

ii) Relationship with TTP

These studies found mixed results in relation to 'perceived risk' and TTP. In one study lower perceived risk was linked to shorter TTP (Friedman et al., 2006), whereas there was no significant relationship between perceived risk and TTP in a study by Smith et al. (2009).

Access to Healthcare

i) Robustness of measures

Seven studies evaluated the relationship between 'access to healthcare' and TTP. Three of these studies (Kumar et al., 2001, O'Mahony et al., 2013, Scott et al., 2008) used a scale with some evidence of reliability or validity.

Kumar et al. (2001) examined availability of transport, visiting a doctor for early detection and regular visit to the doctor as part of a 60 item questionnaire. No details on the items were provided. Test-retest reliability of the final questionnaire was acceptable (ICC = .81).

Health service utilisation (O'Mahony et al., 2013)[1] was measured using an 11 item modified version of the 13 item 'Perceived Access to Health Care Services Scale' (Facione et al., 1997). Cronbach's alpha for the original scale was .78 (Facione et al., 1997), whereas O'Mahony et al. (2013)[1] reported a lower Cronbach's alpha (α = .64) for the modified scale. The average content validity index for the scale was .90 (O'Mahony et al., 2013)[1]. Further, personal experience of prejudice in health care delivery was assessed in this study via the 'Personal Experience of Prejudice Scale' (Facione et al., 2002). The average content validity index for the scale was .85 (O'Mahony et al., 2013)[1]. Both internal consistency (Cronbach's α = .42) and mean inter-item correlations (r = .24) were low in O'Mahony's (2013)[1] study in contrast to studies by Facione et al. (2002) and Facione and Facione (2007) who reported a

Cronbach's alpha of α = .71 and α = .73 respectively, with item total correlations ranging from r = .49 to r = .62.

Scott et al. (2008) examined perceived behavioural control to determine participants' perceived ability to obtain help for their oral symptoms. The authors stated that the scale demonstrated a Cronbach's alpha of α = .70.

ii) Relationship with TTP

Two studies, with some evidence of reliability or validity found no relationship between 'access to healthcare' and TTP (O'Mahony et al., 2013; Kumar et al. (2001). Two further studies noted a significant link between 'access to healthcare' and shorter TTP (Cameron and Hinton, 1968, Scott et al., 2008). These latter studies used measures that either had no evidence of reliability or validity (Cameron and Hinton, 1968), or only evidence of reliability (Scott et al., 2008).

Emotional Response to symptoms

i) Robustness of measures

Thirteen studies investigated 'emotional response' to symptoms. Eight of these studies (Forghieri et al., 2010, Friedman et al., 2006, Hashim et al., 2010, O'Mahony and Hegarty, 2009, O'Mahony et al., 2013, Reifenstein, 2007, Scott et al., 2008, Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Five studies (Forghieri et al., 2010, Friedman et al., 2006, O'Mahony and Hegarty, 2009, O'Mahony et al., 2013, Scott et al., 2008) used (a modified version of) the 'Symptom Distress Scale' (Meechan et al., 2003). Cronbach's alpha was α = .89 in the original study (Meechan et al., 2003) and ranged from α = .88 to α = .94 in the five studies that used a modified version.

Reifenstein (2007) measured fear in relation to symptom interpretation by an 11-item 'Fear Scale', which was developed for the study to measure correlation of fear with days delayed in seeking care. The 'Fear Scale' demonstrated good reliability in both the pilot (Cronbach's α = .97) and actual study (Cronbach's α = .95). Face validity of the questionnaire was assessed by a panel of nursing experts and a team of five psychological experts.

Hashim et al. (2010) investigated concern of rectal bleeding via a self-administered questionnaire. The authors did not provide further details on the items used, but noted that face validity was determined by a pre-test in six subjects. Further, the questionnaire was validated by an expert panel consisting of a colorectal surgeon, primary care physicians and a psychiatrist.

Initial worry was assessed by Unger-Saldana et al. (2012) as part of the 'Patient initial interpretation of symptoms' dimension within the questionnaire. Convergent and divergent validity were examined and the initial worry item demonstrated moderate to strong degrees of correlation with other items within the 'Patient initial interpretation of symptoms' dimension (r = .52 to r = .72) and no or low correlations with items from other dimensions. Face and content validity of the entire questionnaire was assessed in the questionnaire development process.

ii) Relationship with TTP

Regardless of the evidence of reliability or validity for the measures of emotion, the findings for a link between 'emotional response' and TTP were mixed, varying between no association and emotion leading to shorter TTP (Cameron and Hinton, 1968, Hashim et al., 2010, Li et al., 2012, O'Mahony and Hegarty, 2009, O'Mahony et al., 2013). Findings differed between emotions, for instance, in the study by O'Mahony and Hegarty (2009) only anxiety was related to shorter TTP. Two studies (Panzarella et al., 2014, Risberg et al., 1996)

found an association between emotion [denial (Panzarella et al., 2014) and distress (Risberg et al., 1996)] and increased TTP. All of the other emotional responses examined in this study ('fear', 'carelessness', 'medical services mistrust') revealed no significant relationship.

Symptom Interpretation

i) Robustness of measures

Fourteen studies assessed 'symptom interpretation'. Four studies provided some evidence of the reliability or validity of the measure used (Hashim et al., 2010, Kumar et al., 2001, O'Mahony et al., 2013, Unger-Saldana et al., 2012).

O'Mahony et al. (2013)[1] used an adapted version of the 'Illness Perception Questionnaire' (Weinman et al., 1996) to measure beliefs regarding breast cancer. The 26-item adapted version measured beliefs relating to symptom cause, timeline, consequences, cure/control and symptom outcome. In O'Mahony's study (2013)[1] internal consistency coefficients ranged from $\alpha = .50$ to $\alpha = .79$, whereas in the original study (Weinman et al., 1996) reliability coefficients ranged from $\alpha = .73$ to $\alpha = .82$. Two items on symptom outcome were added to the modified version of the 'Illness Perception Questionnaire' using questions adapted from a qualitative study conducted by Burgess et al. (1998). Further, O'Mahony et al. (2013)[1] noted that the average content validity index for scales was .80 for duration, .90 for consequences and .90 for cure/control. The average content validity index for items ranged from .80 to 1.00 for cause and 1.00 for outcome of symptoms (O'Mahony et al., 2013)[1]. Concurrent, discriminative and predictive validity and test-retest reliability of the 'Illness Perception Questionnaire' was established in the original study (Weinman et al., 1996).

Perceived seriousness was assessed by Unger-Saldana et al. (2012) as part of the 'Patient initial interpretation of symptoms' questionnaire dimension. Convergent and divergent validity were examined and items within the 'Patient initial interpretation of

symptoms' dimension demonstrated moderate to strong degrees of correlation with each other (r = .52 to r = .72) and not with items from other dimensions. Internal consistency for this dimension was reported as Cronbach's α = .77 (p < .001). Face and content validity of the entire questionnaire was assessed in the questionnaire development process. As noted earlier, test-retest examinations were conducted, but the authors did not indicate the test-retest correlation for each separate dimension of the questionnaire.

Hashim et al. (2010) investigated causes of rectal bleeding according to patients opinion via a self-administered questionnaire. Face validity was determined by a pre-test in six subjects. Further, questionnaires were validated by an expert panel.

Kumar et al. (2001) examined perceived necessity of consulting a doctor for small ulcers in the mouth for those who use tobacco as part of a 60 item questionnaire. Test-retest reliability of the final questionnaire was acceptable (ICC = .81).

'Symptom interpretation' was found to be related to TTP in six studies (Andersen and Cacioppo, 1995, Greer, 1974, Kakagia et al., 2013, Oliveria et al., 1999, O'Mahony et al., 2013, Panzarella et al., 2014). There was no association between 'symptom interpretation' and TTP in two studies (Mansson et al., 1993, Smith and Anderson, 1987). Only one study used a measure with evidence of reliability and validity (O'Mahony et al., 2013).

Social Factors

i) Robustness of measures

The extent to which 'social factors' affected TTP was assessed in ten studies. Six studies provided some evidence of the reliability or validity of the measure (Cochran et al., 1986, Hashim et al., 2010, Kumar et al., 2001, O'Mahony et al., 2013, Reifenstein, 2007, Unger[18] Saldana et al., 2012).

Kumar et al. (2001) examined whether participants were escorted by someone, whether any family member, relative or friends had cancer and family tension due to long treatment. Test-retest reliability was acceptable (ICC = .81).

O'Mahony et al. (2013)[1] examined constraints on help-seeking via an adapted version of the 17 item 'Constraint scale' (Facione and Facione, 2007). Cronbach's alpha was reported as α = .76 in the original study (Facione et al., 2002). O'Mahony et al. (2013)[1] noted that reliability for this scale was not established as the scores were not summed. The content validity index for the adapted version was .88.

Reifenstein (2007) examined social norm in relation to help-seeking behaviour using a scale developed by Lauver (1994). Cronbach's alpha was α = .97 in Reifenstein's study (2007). In the original study (Lauver, 1994) Cronbach's alpha ranged from α = .84 to α = .88, and test-retest reliability was r = .67.

Marital satisfaction was assessed by Cochran et al. (1986) using the 'Dyadic Adjustment Scale' (Spanier, 1976). Although Cochran et al. (1986) reported no further details on the reliability of the scale Cronbach's alpha was reported as α = .96 in the original study by Spanier (1976). Content and construct validity of the scale was established in the original study (Spanier, 1976). Further, factor analysis of the final 32 item scale revealed that the scale measures the theoretical construct to some extent. In addition to the 'Dyadic Adjustment Scale' (Spanier, 1976) participants also completed measures of tangible support (adapted from Schaefer et al., 1981) using a 9-item Guttman scale. Cochran et al. (1986) did not state whether tangible support was subjected to a formal assessment of validity and reliability. However, in the original study internal consistency for the 9-item tangible support scale was α = .31 and test-retest reliability was reported as r = .56 (Schaefer et al., 1981).

Emotional support was assessed by Unger-Saldana et al. (2012) as part of the 'Social network support for seeking medical attention' dimension of the questionnaire. Convergent

and divergent validity were examined, however items within the 'Social network support for seeking medical attention' dimension correlated poorly with each other (r = < .30). The authors also indicated that internal consistency (Cronbach's alpha) was low, resulting in the items being used individually rather than a summed scale. Face and content validity of the entire questionnaire was assessed in the questionnaire development process.

ii) Relationship with TTP

For those measures with some evidence of validity, 'social factors' were generally linked to shorter TTP (Cochran et al., 1986, Hashim et al., 2010, O'Mahony et al., 2013). Those measures that lacked validity often showed no association with TTP (Kumar et al., 2001, Reifenstein, 2007), although two studies using measures with no evidence of reliability or validity also linked 'social factors' to shorter TTP (Cochran et al., 1986, Li et al., 2012).

Coping Methods

i) Robustness of measures

'Coping methods' were assessed in seven studies. All studies but one (Prohaska et al., 1990) mentioned some evidence of reliability or validity of the scale.

Forghieri et al. (2010) and Reifenstein (2007) examined coping using the 'Ways of Coping Scale' (Folkman and Lazarus, 1988). The scale has demonstrated good reliability with Cronbach's alpha ranging from $\alpha = .61$ to $\alpha = .79$ (Folkman and Lazarus, 1988).

Denial was measured by Reifenstein (2007) using a 9-item 'Denial Scale' to assess the correlation of denial with days delayed in seeking care. Reliability of the scale was assessed in both the pilot (Cronbach's $\alpha = .88$) and actual study (Cronbach's $\alpha = .63$). Denial was also assessed with the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1988). Moreover, confrontive coping, social support strategies, and problem-solving strategies were assessed using the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1988). However,

no correlation was found between the escape/avoidance subscale of the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1988) and the newly established 'Denial scale' when assessing construct validity of the newly established 'Denial scale'. Face validity of the scale was determined by a psychologist and a panel of nursing experts.

Coping styles as measured by a short version of the 'Utrecht Coping List' (Schreurs et al., 1993) were examined by Tromp et al. (2005). Tromp et al. (2005) did not provide any information on the number of items or psychometric properties of the scale. However, the original 44-item scale has demonstrated moderate to good internal consistency (α = .64 to α = .82) and reasonable test–retest reliability (r = .52 to r = .79) (Schreurs et al., 1993).

Kumar et al. (2001) examined domestic remedies/medicine before consulting a doctor. Test-retest reliability was acceptable (ICC = .81).

The use of alternative medicine was assessed by Unger-Saldana et al. (2012). Face and content validity of the entire questionnaire was assessed in the questionnaire development process but no reliability data was given for this specific question.

ii) Relationship with TTP

'Coping methods' were generally associated with longer TTP (Reifenstein, 2007, Tromp et al., 2005). Nevertheless, Reifenstein (2007) noted that for the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1998) only 'confrontive coping', 'seeking social support' and 'problem-solving' strategies were associated with shorter TTP. Both of these studies used scales with some evidence of reliability. A study by Kumar et al. (2001), which only had evidence of reliability found no link between 'coping methods' and TTP.

Discussion

Principal findings

This is the first systematic literature review examining the robustness with which psychosocial factors that may affect TTP for symptoms of cancer are quantitatively measured. The vast majority of studies failed to report the use of valid and reliable measurements. The measurement tools available to understand influences on help□seeking behaviour and to measure the impact of interventions to encourage early diagnosis are limited. It is not necessarily the case that the measures are not valid or reliable of course, but at present little formal psychometric testing appears to have been conducted and thus the robustness and trustworthiness of these instruments is unknown. The relationship between psychosocial factors and TTP is mixed and this may be due to the absence of valid and reliable measures.

This systematic review has highlighted that when no or minimal evidence was present, results were inconclusive or differed to those studies which used reliable and valid measures (particularly the case for reasons for help□seeking, risk perception, access to healthcare, knowledge, social factors and coping methods). For some psychosocial factors (e.g. reasons for delay, symptom interpretation) the lack of psychometrically tested measures prevented clear conclusions to be made about the results of the study and the quality of the measures. For measures of emotion, the specific emotion being measured, rather than the measure itself appeared to impact the results.

Strengths and limitations

The main strengths of this review were the systematic search for literature across five databases (medical, psychological and social scientific) and five existing systematic reviews

(Macdonald et al., 2006, Macdonald et al., 2004, Mitchell et al., 2007, Ramirez et al., 1999, Richards et al., 1999). An additional strength of this review is the inclusion of studies in any language, reducing the potential for bias introduced by the exclusion of papers published in non-English language journals.

Nevertheless, this review may be subject to limitations. Publications in this area are spread over many journals across different fields, and it is possible that some articles were overlooked through variable indexing and use of subject headings. There may also be evidence of reliability or validity of some of the existing scales when used in non-cancer contexts that has been missed. Furthermore, Macdonald et al.'s (2004) systematic review excluded studies on breast cancer. In turn some publications pertaining to help-seeking behaviour for breast cancer may have been overlooked.

Methodological issues in existing research

The availability of reported psychometric properties of measures varied between the different types of psychosocial factors. The proportion of measures with any form of assessment of reliability or validity was as follows: 0% (0 out of 3) for risk perception, 18% (3 out of 17) for reasons for delay, 22% (4 out of 18) for symptom interpretation, 33% (2 out of 6) for reasons for seeking help, 38% (3 out of 8) for knowledge, 50% (8 out of 16) for emotional response, 55% (6 out of 11) for access to healthcare, 60% (9 out of 15) for social factors, and 86% (6 out of 7) for coping methods. In many cases, only one form of validity or reliability was assessed. Overall, when reliability or validity of measures were tested this was often only cursory. For example, in terms of reliability, if it was established, the main type reported was internal consistency, and this was not common in newly developed measures. The most commonly reported forms of validity were face validity and content validity, but most new scales were not tested for either form. This review did not critically assess the quality of the

psychometric testing. Further investigation of the methods used to establish reliability and validity is likely to reveal further weaknesses in the strength of the evidence of some claims of reliability and validity in this area.

Conclusion and implications for subsequent studies

The review highlighted numerous methodological and design issues regarding how psychosocial factors influencing help-seeking behaviour are measured. The majority of studies developed new items or scales yet more attention must be given to how scales or items are developed and how robust the new measures are. The usage of measurements that lack reliability or validity may impede the conclusions drawn from the study. If an invalid measure is used inaccurate assumptions may be made.

Consequently, to improve the methodological quality of future studies that assess how psychosocial factors influence TTP for symptoms of cancer it is recommended that where possible researchers use existing measures that display adequate reliability and validity rather than developing new measures. Measures used by O'Mahony et al. (2013) to assess access to healthcare, social factors, emotional response to symptoms, beliefs about symptoms, and knowledge of breast cancer, and measures used by Unger-Saldaña et al. (2012) to assess perceived seriousness of symptoms and perceived reasons for delay each had evidence of both reliability and validity. It should be noted that the measure by Unger-Saldaña et al. (2012) is currently only available in Spanish and would need to be translated into English and then undergo further testing to achieve equivalence between the original version and the translated version (Streiner et al., 2015). However, there is an overall lack of psychometrically sound measures, especially for reasons for delay, symptom interpretation and risk perception in this context, and thus new measures may be needed. If researchers choose to develop new measures, adequate consideration should be given to the development

of a measure to ensure that they contain adequate psychometric properties in order to robustly determine the how the aforementioned factors affect TTP for symptoms of cancer.

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Table 1. Evidence of reliability and validity in measures used to assess psychosocial contributing factors to TTP

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Reasons for delay										
Subjective patient-specific factors	(Alam, 2011)	Self	New	-	-	-	-	-	-	-
Reasons for delay	(Bosl et al., 1981)	Medical Records	-	-	-	-	-	-	-	-
Reason for delay	(Courtney et al., 2012)	Self	New	-	-	-	-	-	-	-
Reasons for delay	(Doherty and MacKie, 1986)	Interviewer	New	-	-	-	-	-	-	-
Barriers to seeking a medical consultation	(Friedman et al., 2006)	Self	New	-	-	-	-	-	-	= [2]
Reasons delaying presentation	(Kakagia et al., 2013)	Interviewer	New	-	-	-	-	-	-	- [3]
Competing life priorities	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	[4]
Factors which made it more difficult to visit GP	(O'Mahony et al., 2009)	Self	Existing (Meechan et al. 2002, 2003. Modified for study)	-	-	-	-	-	-	[5]
Barriers to seeking help	(Popescu et al., 2013)	Self	New	-	-	-	-	-	-	-

[1] = longer TTP; [2] = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

[2] 'More likely to identify cost' ($p < 0.001$) and 'not wanting to think about it' associated with longer TTP in between group comparisons. Other barriers ('hard to get an appointment', 'hard to get off work', 'worried it might be cancer', 'worried about cancer treatment', 'worried that I might lose my breast' and 'too long a wait at the clinic') not associated with TTP in between group comparisons.

[3] 'Embarrassment' ($p = 0.003$; OR = 1.33; CI = 0.8–2.3), 'fear of investigations and management' ($p = <0.001$; OR = 3.12; CI = 1.6–6.1), 'wait and see' ($p = <0.001$; OR = 5.09; CI = 2.6–9.9), 'low prioritisation' ($p = <0.001$; OR = 2.11; CI = 1.9–5.8), 'self-medication' ($p = <0.001$; OR = 2.37; CI = 0.9–6.3), 'fatalism/nihilism' ($p = <0.001$; OR = 4.21; CI = 2.2–8.2) and 'denial' ($p = <0.001$; OR = 2.74; CI = 1.4–5.3) associated with longer TTP. 'Fear of diagnosis' not associated with longer TTP.

[4] 'I considered the symptom as harmless' ($r = 0.34$, $p = 0.003$), 'I considered the symptom as temporary' ($r = 0.30$; $p = 0.01$), 'my lifestyle is too complex' ($r = 0.29$; $p = 0.01$), 'I had nobody to talk to about the symptom' ($r = 0.28$; $p = 0.02$) and 'I thought I would wait a while before making an appointment' ($r = 0.26$; $p = 0.02$) associated with longer TTP.

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Barriers to seeking medical care	(Prohaska et al., 1990)	Interviewer	New	-	-	-	-	-	-	[1] - [3]
Reasons for delays	(Richard et al., 2000)	Interviewer	New	-	-	-	-	-	-	-
Barriers	(Reifenstein, 2007)	Self	Existing (Lauver, 1994. Modified for study)	[1]	-	-	-	-	-	-
Reasons for delay in diagnosis	(Schmid-Wendtner et al., 2002)	Interviewer	New	-	-	-	-	-	-	-
Competing events in the participants' lives	(Scott et al., 2008)	Self	Existing (Holmes and Rahe, 1967. Modified for study)	-	[1]	-	-	-	-	[1]
Reasons for delay	(Skeppner et al., 2012)	Interviewer	New	-	-	-	-	-	-	-
Reasons for delay	(Smith and Anderson, 1987)	Self	New	-	-	-	-	-	-	-
Patient's perceived reasons for patient delay	(Unger-Saldana et al., 2012)	Interviewer	New	[1]	?	[1]	[1]	[1]	-	-
Reasons for seeking help										
Reason for consulting	(Brochez et al., 2001)	Interviewer	New	-	-	-	-	-	-	-
Triggers for seeking medical advice	(Courtney et al., 2012)	Self	New	-	-	-	-	-	-	-
Factors which made it easier to visit GP	(O'Mahony and Hegarty, 2009)	Self	Existing (Meechan et al. 2002, Meechan et al. 2003. Modified for study)	-	-	-	-	-	-	[3]

[5] 'Thought doctor couldn't help' associated with shorter TTP (r = [illegible], p < 0.05). No significant association between TTP and other barriers ('transportation problems', 'difficulty getting off work', 'not knowing where to go for help', 'just being too busy', 'thought it was not serious', 'not comfortable with doctor' and 'fear').
[6] 'I considered the symptom as harmless' (r = 0.28; p = 0.01), 'the earlier I got it seen to the better' (r = 0.25; p = 0.02) and 'the nature of the symptom' (r = 0.25; p = 0.03) associated with shorter TTP.

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Reasons for the rapidity of the visit to the physician	(Richards, 2009)	Interviewer	New	-	-	-	-	-	-	-
Utility	(Reifenstein, 2007)	Self	Existing (Lauver, 1992a)	[24]	[24]	-	-	-	-	-
Patient's reason for seeking medical care	(Unger-Saldana et al., 2012)	Interviewer	New	-	-	[11]	[11]	-	-	-
Knowledge										
Symptom Information	(Bowen and Rayner, 2002)	Self	New	-	-	-	-	-	-	-
Cancer can develop if tobacco is used	(Kumar et al., 2001)	Self	New	-	[13]	-	-	-	-	-
Knowledge	(Oliveria et al., 1999)	Interviewer	New	-	-	-	-	-	-	-[7]
Breast Cancer Knowledge	(O'Mahony et al., 2013, O'Mahony et al 2011)	Self	Existing (Facione et al. 2002. Modified for study)	[18]	-	[18]	[18]	-	-	[18]
Knowledge of cancer (general or oral)	(Panzarella et al., 2014)	Interviewer	New	-	-	-	-	-	-	[9] -[7]
Knowledge about cutaneous melanoma	(Schmid-Wendtner et al., 2002)	Interviewer	New	-	-	-	-	-	-	-
Knowledge and beliefs about oral cancer	(Scott et al., 2008)	Self	Existing (Humphris et al. 1999)	[8]	-	-	-	-	[8]	[8]
Knowledge of lung cancer symptoms	(Smith et al., 2009)	Interviewer	New	-	-	-	-	-	-	[10]
Perceived Risk										
Perceived risk of breast cancer	(Friedman et al., 2006)	Self	New	-	-	-	-	-	-	[6]
Risk Perception	(O'Mahony and Hegarty, 2009)	Self	New	-	-	-	-	-	-	-

[7] Knowledge of 'bleeding' (OR = 0.43; CI = 0.19–0.94) or 'scab not healing' (OR = 0.46; CI = 0.21–1.00) as a sign of skin cancer not associated with TTP.
[8] Shorter TTP associated with 'knowledge of breast symptom identity' (i.e. recognising the presenting symptom of a breast lump) (OR = 0.54; p < 0.001) and 'breast cancer knowledge' (i.e. responding 'yes' to 'a clear drainage from the nipple') (OR = 0.63; p = 0.040). Shorter TTP associated with 'knowledge relating to breast symptom identity' (i.e. a presenting symptom of 'nipple indrawn/changes') (OR = 4.80; p = 0.005).
[9] General knowledge of cancer (Poor vs. Basic: OR = 52.91; 95% CI = 51.25–6.76; p = 0.013) linked to shorter TTP. No significant association between TTP and knowledge of oral cancer.

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Perceptions of self-risk of cancer	(Smith et al., 2009)	Interviewer	New	-	-	-	-	-	-	=
Access to Healthcare										
Ease vs. difficulty to access	(Adrien et al., 2014)	Self	New	-	-	-	-	-	-	-
Difficulty to consult a general practitioner	(Adrien et al., 2014)	Self	New	-	-	-	-	-	-	-
Previous hospital experience	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	[3]
Attitude towards the family doctor	(Greer, 1974)	Interviewer	New	-	-	-	-	-	-	-
Financial Constraints	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	-
Regular visit to doctor in the past 12 years	(Kumar et al., 2001)	Self	New	-	[3]	-	-	-	-	=
Visiting doctor for early detection	(Kumar et al., 2001)	Self	New	-	[3]	-	-	-	-	-
Availability of transport	(Kumar et al., 2001)	Self	New	-	[3]	-	-	-	-	?
Health Service System Utilisation (Perceived access)	(O'Mahony et al., 2013)	Self	Existing (Facione et al. 1997. Modified for study)	[3]	-	-	[3]	-	-	=
Health Service System Utilisation (Prejudice in health care delivery)	(O'Mahony et al., 2013)	Self	Existing (Facione and Facione, 2007. Modified for study)	[3]	-	-	[3]	-	-	=
Perceived Behavioural Control	(Scott et al., 2008)	Self	New	[3]	-	-	-	-	-	[3]
Emotional Response										
Illness inference (Negative affect)	(Anderson and Cacioppo, 1995)	Interviewer	New	-	-	-	-	-	-	-
Degree of anxiety on discovering the lump in the breast	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	[3]
Attitude to the forthcoming operation	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	-
Emotional response	(Forghieri et al., 2010)	Self	Existing (Meechan et al. 2003)	[3]	-	-	-	-	-	-

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Initial emotional response to noticing breast symptom	(Friedman et al., 2006)	Self	Existing (Meechan et al. 2003. Modified for study)	[5]	–	–	–	–	–	=
Concern of rectal bleeding	(Hashim et al., 2010)	Self	New	–	–	[10]	[10]	–	–	[10]
Fear of cancer diagnosis	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	–
Fear in response to symptom(s)	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	[11]
Symptom preoccupation	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	[11]
Emotional response to symptom discovery	(O'Mahony et al., 2013, O'Mahony et al, 2011)	Self	Existing (Meechan et al. 2003. Modified for study)	[5]	–	–	[5]	–	–	[10]
Emotional response when first noticing breast symptom	(O'Mahony and Hegarty, 2009)	Self	Existing (Meechan et al. 2003. Modified for study)	[5]	–	–	–	–	–	[11]
Emotional responses to the detection of potentially threatening oral symptoms	(Panzarella et al., 2014)	Interviewer	New	–	–	–	–	–	–	– [12]
Fear	(Reifenstein, 2007)	Self	New	[10]	–	[10]	–	–	–	=
Distress	(Risberg et al., 1996)	Self	New	–	–	–	–	–	–	[10]
Emotional distress	(Scott et al., 2008)	Self	Existing (Meechan et al. 2003. Modified for study)	[5]	–	–	–	–	–	=
Initial worry	(Unger-Saldana et al., 2012)	Interviewer	New	–	–	[11]	[11]	[11]	–	–
Symptom interpretation										

[10] Emotional response of being 'afraid' on symptom discovery (OR = 0.37; p = 0.005) associated with shorter TTP.
[11] Emotional response of being 'anxious' on symptom discovery (r = 0.31; p = 0.003) associated with shorter TTP.
[12] Emotional response of 'denial' associated with longer TTP (True vs. False: OR = 56.84; 95% CI = 52.31–20.24; p < 0.01). No significant relationship between TTP and other emotional responses ('fear', 'carelessness', 'medical service mistrust').

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Environmental distractions	(Andersen and Cacioppo, 1995)	Interviewer	New	-	-	-	-	-	-	
Illness inference (Symptom salience, motivation to determine the cause of symptoms, perceived seriousness)	(Andersen and Cacioppo, 1995)	Interviewer	New	-	-	-	-	-	-	[13]
Awareness of the significance of their symptoms	(Bowen and Rayner, 2002)	Self	New	-	-	-	-	-	-	-
Initial reaction to Breast Symptoms	(Greer, 1974)	Interviewer	New	-	-	-	-	-	-	[8]
Causes or rectal bleeding according to patients opinion	(Hashim et al., 2010)	Self	New	-	-	[11]	[11]	-	-	-
Symptom Interpretation	(Kakagia et al., 2013)	Interviewer	New	-	-	-	-	-	-	[8]
Necessity of consulting a doctor for small ulcers in the mouth for tobacco users	(Kumar et al., 2001)	Self	New	-	[1]	-	-	-	-	?
Symptom Interpretation	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	-
How seriously the patients viewed their first symptoms of bladder cancer	(Mansson et al., 1993)	Self	New	-	-	-	-	-	-	=
Beliefs relating to symptom cause, timeline, consequences, curability/control and outcome	(O'Mahony et al., 2013, O'Mahony et al., 2011)	Self	Existing (Weinman et al. 1996. Modified for study)	[8]	[8]	-	[8]	[8]	[8]	[8][14]
Low awareness of melanoma signs/ symptoms	(Oliveria et al., 1999)	Interviewer	New	-	-	-	-	-	-	[8]
Initial self-diagnosis	(Panzarella et al., 2014)	Interviewer	New	-	-	-	-	-	-	[8]
Complete unawareness	(Panzarella et al., 2014)	Interviewer	New	-	-	-	-	-	-	[8]
Recognition of symptom seriousness	(Ristvedt and Trinkaus, 2005)	Self	New	-	-	-	-	-	-	-
Attributions about the cause of	(Ristvedt and	Self	New	-	-	-	-	-	-	-

[13] Patients reported motivation to evaluate their symptoms ($r = .42$; $p < 0.05$) and more dominant cancer inferences when symptoms first detected ($r = .32$; $p < 0.01$) associated with shorter TTP.
[14] Longer TTP associated with women's belief in longer symptom duration (OR = 1.18; p = 0.023).

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
their symptoms	Trinkaus, 2005)									
Perceived cause	(Smith and Anderson, 1987)	Self	New	-	-	-	-	-	-	=
Perceived seriousness	(Smith and Anderson, 1987)	Self	New	-	-	-	-	-	-	=
Perceived seriousness	(Unger-Saldana et al., 2012)	Interviewer	New	[5]	?	[5]	[5]	[5]	-	-
Social factors										
Encouragement from others to see their GP	(Bowen and Rayner, 2002)	Self	New	-	-	-	-	-	-	-
Knowledge of others with mammary tumours	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	-
Willingness to tell others about personal troubles	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	-
Emotional Support	(Cochran et al., 1986)	Interviewer and Self	Existing (Stewart, 1983. Modified for study)	-	-	-	-	-	-	[3]
Tangible Support	(Cochran et al., 1986)	Interviewer and Self	Existing (Schaefer et al. 1981. Modified for study)	?	[3]	-	-	-	-	=
Marital Satisfaction	(Cochran et al., 1986)	Interviewer and Self	Existing (Spanier, 1976. Modified for study)	[5]	-	-	[5]	[5]	[5]	[5]
Experience of mastectomy among family and friends	(Greer, 1974)	Interviewer	New	-	-	-	-	-	-	-
Seeking advice	(Hashim et al., 2010)	Self	New	-	-	[5]	[5]	-	-	[5]
Escorted by someone	(Kumar et al., 2001)	Self	New	-	[3]	-	-	-	-	=
Any family member/relative/friends had cancer	(Kumar et al., 2001)	Self	New	-	[3]	-	-	-	-	=
Family tension due to long treatment	(Kumar et al., 2001)	Self	New	-	[3]	-	-	-	-	?
Symptom disclosure	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	[5]

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
Social Factors (Role obligations, Symptom disclosure)	(O'Mahony et al., 2013)	Self	Existing (Facione et al. 2002. Modified for study)	[11]	–	–	[11]	–	–	[11]
Social Norm	(Reifenstein, 2007)	Self	Existing (Lauver, 1994. Modified for study)	[10]	[10]	–	–	–	–	–
Social network support for seeking medical attention	(Unger[5]Saldana et al., 2012)	Interviewer	New	?	–	[11]	[11]	?	–	–
Coping Methods										
Ways of Coping	(Forghieri et al., 2010)	Self	Existing (Folkman and Lazarus, 1998)	[8]	–	–	–	–	–	–
Self-treatment	(Hashim et al., 2010)	Self	New	–	–	[11]	[11]	–	–	–
Domestic remedies/medicine before consulting a doctor	(Kumar et al., 2001)	Self	New	–	[11]	–	–	–	–	–
Illness behaviours (coping and self[5]help practices)	(Prohaska et al., 1990)	Interviewer	New	–	–	–	–	–	–	–
Denial	(Reifenstein, 2007)	Self	New							[10]
			Existing (Folkman and Lazarus, 1998)	[8]	–	[8]	–	?	–	[10][8]
Coping Style	(Tromp et al., 2005)	Self	Existing (Schreurs et al. 1993)	[6]	[6]	–	–	–	–	[11]
Use of alternative medicine	(Unger[5]Saldana et al., 2012)	Interviewer	New	–	–	[11]	[11]	–	–	–

[11] Social factors of symptom disclosure to another person (OR = 0.24; p < 0.001) and 'not applicable' response to social constraints relating to family commitments (OR = 0.38; p = 0.007) associated with shorter TTP.

[10] Regarding the 'Denial Scale' (Reifenstein, 2007) more denial (r = 0.36; p < 0.05) associated with longer TTP. Regarding the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1998) only 'confrontive coping' (r = [8].32; p < 0.05), 'seeking social support' (r = [8].37; p < 0.05), and 'problem solving' (r = [8].32; p < 0.05) strategies associated with shorter TTP. 'Escape avoidance', 'distancing', 'self[5]controlling', 'accepting responsibility' and 'positive reappraisal strategies' not significantly associated with TTP.

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This document is a supplement to the manuscript submitted to Journal of Health Psychology, titled "Measures of psychosocial factors that may influence help-seeking behaviour: A systematic review of psychometric properties"

The supplement includes:

1. Supplementary Data File 1: Search Strategy (for OVID Medline)
2. Supplementary Data File 2: PRISMA Flow Diagram
3. Supplementary Data File 3: PRISMA Checklist
4. Supplementary Data File 4: Study characteristics

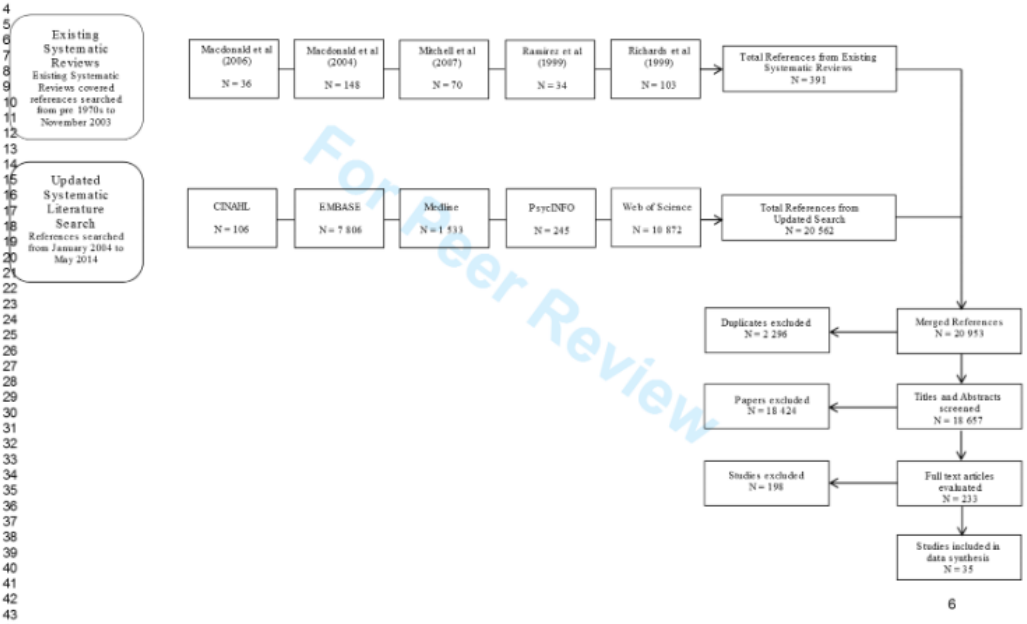
Supplementary Data File 1: Search Strategy (for OVID Medline)

Table 1. Search Strategy for OvidSP Medline

#	Searches
1	exp Neoplasms/
2	exp Delayed Diagnosis/
3	exp Early Diagnosis/
4	exp Time Perception/
5	exp Time-to-Treatment/
6	wait$.mp
7	postpon$.mp.
8	late$.mp.
9	duration.mp.
10	interval$.mp.
11	ignore$.mp.
12	dismiss$.mp.
13	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14	exp Primary Health Care/
15	exp Health Services Accessibility/
16	exp Health Services/
17	exp Referral and Consultation/
18	exp Patient Acceptance of Health Care/
19	exp physicians/
20	present$.mp.
21	attend$.mp.
22	consult$.mp.
23	sought.mp.
24	consider.mp.
25	help adj3 seek$
26	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27	symptom$.mp.
28	sign$1.mp.
29	onset.mp.
30	notic$3.mp.
31	detect.mp.
32	aware$.mp.
33	recogni$.mp.
34	27 or 28 or 29 or 30 or 31 or 32 or 33
35	exp emotions/
36	exp anxiety/
37	exp attitude to health/
38	exp Attitude of Health Personnel/
39	exp attitude/
40	exp patient compliance/
41	exp social support/
42	exp health behavio?r/
43	anx*4.mp.
44	attitude$.mp.
45	distress$.mp.
46	worr*3.mp.

47	concern$.mp.
48	embarrass$.mp.
49	discourag$.mp.
50	reassur$.mp.
51	emotion$.mp.
52	belie$.mp
53	perceive$.mp.
54	interpret$.mp.
55	access$.mp.
56	reason$.mp.
57	priorit$.mp.
58	percep$.mp.
59	cognit$.mp.
60	behav$.mp.
61	psychosocial.mp.
62	35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61
63	exp questionnaires/
64	exp psychometrics/
65	measur$.mp.
66	assess$.mp.
67	scale$.mp.
68	instrument$.mp.
69	survey$.mp.
70	quantitative$.mp.
71	63 or 64 or 65 or 66 or 67 or 68 or 69 or 70
72	1 and 13 and 26 and 34 and 62 and 71
73	limit 72 to yr="2004-2014"

Supplementary Data File 2: PRISMA Flow Diagram



6

Supplementary Data File 3: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2-3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3-4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4-5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4-5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplemental Data File 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5-6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	N/A

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6 and Supplemental Data File 2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	6 and Supplemental Data File 4
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	6-19 and 26-29
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			

Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	20-24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	21
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23-24
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	XXX undertook this research project as a graduate research student funded through a XXX internal scholarship. No additional external finding was received for the project.

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Supplementary Data File 4: Study characteristics

Table 1. Study Characteristics

Authors (Year)	Country	Sample (n)	Cancer Type	Aims To identify…
Adrien et al. (2014)	France	668	Head and neck	Healthcare inequalities and socio-economic factors influencing late-stage diagnosis.
Alam (2011)	USA	860	Skin	Reasons for delayed presentation for diagnosis and treatment.
Andersen and Cacioppo (1995)	USA	34	Gynaecological malignancies	Inferences and decisions an individual makes as time passes from symptom detection to consulting with a HCP.
Bosl et al. (1981)	USA	335	Germ-cell testicular	Extent and causes of diagnostic delay, and impact of delay on disease stage.
Bowen and Rayner (2002)	UK	37	Lung	Time between symptom occurrence and presentation to GP.
Brochez et al. (2001)	Belgium	130	Skin	Diagnostic pathway, patient and physician delay and factors related to it.
Cameron and Hinton (1968)	UK	83	Breast	If certain aspects of the tumour, patients' personalities or social background were linked to consultation delay.
Cochran et al. (1986)	USA	37	Endometrial	Physical, interpersonal, and psychological factors associated with delay to identify barriers to early treatment.
Courtney et al. (2012)	Australia	1085	Colorectal	Proportion ever experiencing a symptom in their lifetime and the non-consultation rate for each primary symptom of cancer.
Doherty and MacKie (1986)	UK	125	Skin	Any evidence of inappropriate delay in receiving surgical treatment for a new or changing pigmented lesion.
Forghieri et al. (2010)	Italy	120	Skin	If attitude towards illness of those attending a melanoma screening day differs from those diagnosed via the usual clinical pathway.
Friedman et al. (2006)	USA	99	Breast	Demographic, medical and psychosocial factors related to delay
Greer (1974)	UK	157	Breast	Delay in seeking and obtaining treatment for breast lumps.
Hashim et al. (2010)	Malaysia	80	Colorectal	Prevalence of consultation delay and identifying associated factors
Kakagia et al. (2013)	Greece	513	Skin	Risk factors of patient-related delayed presentation.
Kumar et al. (2001)	India	52	Oral	Psychosocial factors related to delay and the relationship between delay and cancer stage.
Li et al. (2012)	China	425	Breast	Determinants of patient delay in indigenous Chinese women.
Mansson et al. (1993)	Sweden	203	Bladder	Factors influencing patient's delay and doctor's delay.

O'Mahony and Hegarty (2009)	Ireland	99	Breast	Extent of delay and factors influencing help-seeking.
O'Mahony et al. (2013)	Ireland	449	Breast	Help seeking behaviour and associated factors on self-discovery of a breast symptom as depicted in a conceptual framework.
Oliveria et al. (1999)	USA	255	Skin	Relationship between patients' knowledge and awareness of melanoma signs and symptoms and delay for suspicious lesions.
Panzarella et al. (2014)	Italy	156	Oral	Variables linked to delay, mainly cognitive and psychological factors.
Popescu et al. (2013)	Romania	122	Skin	Gender differences in practices and attitudes related to early detection.
Prohaska et al. (1990)	USA	254	Colorectal	Symptom perceptions and illness behaviours prior to diagnosis to determine age patterns and their effect on self-care activities.
Reifenstein (2007)	USA	48	Breast	Care-seeking behaviours of African American women so interventions for breast cancer symptoms can be developed and tested in the future.
	France	590	Skin	Patient- and doctor-related components in the delay before diagnosis and the prognosis of cutaneous melanoma.
Risberg et al. (1996)	Norway	252	Various	Delays involved in diagnosis and treatment and the possible psychological distress associated to the different delay periods.
Ristvedt and Trinkaus (2005)	USA	69	Rectal	Role of negative affective traits in delayed help seeking for symptoms of rectal cancer.
Schmid-Wendtner et al. (2002)	Germany	233	Skin	Extent and consequence of patient and professional delay in diagnosis and treatment.
Scott et al. (2008)	UK	80	Oral	Understanding of patient delay to inform the development of interventions to encourage early presentation of oral cancer.
Skeppner et al. (2012)	Sweden	59	Penile	Initial symptoms and factors linked to patients' and doctors' delay.
Smith and Anderson (1987)	USA	80	Endometrial	Characteristics of symptoms associated with stage and other extent of disease factors at diagnosis.
Smith et al. (2009)	UK	360	Lung	Factors associated with the time taken to consult, with a focus on those from rural and socially deprived areas.
Tromp et al. (2005)	Holland	264	Head and neck	Relationship between relevant health behaviours and health value and control beliefs, as well as psychological distress.
Unger-Saldana et al. (2012)	Mexico	384	Breast	Time intervals from possible cancer detection to the beginning of treatment and the factors predicting prolongation of these intervals.

Appendix 2: Search strategy for Medline

#	Search Terms
1	exp Neoplasms/
2	exp Delayed Diagnosis/
3	exp Early Diagnosis/
4	exp Time Perception/
5	exp Time-to-Treatment/
6	wait$.mp
7	postpon$.mp.
8	late$.mp.
9	duration.mp.
10	interval$.mp.
11	ignore$.mp.
12	dismiss$.mp.
13	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14	exp Primary Health Care/
15	exp Health Services Accessibility/
16	exp Health Services/
17	exp Referral and Consultation/
18	exp Patient Acceptance of Health Care/
19	exp physicians/
20	present$.mp.
21	attend$.mp.
22	consult$.mp.
23	sought.mp.
24	consider.mp.
25	help adj3 seek$
26	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27	symptom$.mp.
28	sign$1.mp.
29	onset.mp.
30	notic$3.mp.

#	Search Terms
31	detect.mp.
32	aware$.mp.
33	recogni$.mp.
34	27 or 28 or 29 or 30 or 31 or 32 or 33
35	exp emotions/
36	exp anxiety/
37	exp attitude to health/
38	exp Attitude of Health Personnel/
39	exp attitude/
40	exp patient compliance/
41	exp social support/
42	exp health behavio?r/
43	anx*4.mp.
44	attitude$.mp.
45	distress$.mp.
46	worr*3.mp.
47	concern$.mp.
48	embarrass$.mp.
49	discourag$.mp.
50	reassur$.mp.
51	emotion$.mp.
52	belie$.mp
53	perceive$.mp.
54	interpret$.mp.
55	access$.mp.
56	reason$.mp.
57	priorit$.mp.
58	percep$.mp.
59	cognit$.mp.
60	behav$.mp.
61	psychosocial.mp.
62	35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61

#	Search Terms
63	exp questionnaires/
64	exp psychometrics/
65	measur$.mp.
66	assess$.mp.
67	scale$.mp.
68	instrument$.mp.
69	survey$.mp.
70	quantitative$.mp.
71	63 or 64 or 65 or 66 or 67 or 68 or 69 or 70
72	1 and 13 and 26 and 34 and 62 and 71
73	limit 72 to yr="2004-2014"

Appendix 3: Search strategy for Embase

#	Search Terms
1	exp Neoplasm/
2	exp Delayed Diagnosis/
3	exp Early Diagnosis/
4	exp Time Perception/
5	exp Time to Treatment/
6	wait$.mp
7	postpon$.mp.
8	late$.mp.
9	duration.mp.
10	interval$.mp.
11	ignore$.mp.
12	dismiss$.mp.
13	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14	exp Primary Health Care/
15	exp Health Care Delivery/
16	exp Health Service/
17	exp patient referral/
18	exp Patient Attitude/
19	exp physician/
20	present$.mp.
21	attend$.mp.
22	consult$.mp.
23	sought.mp.
24	consider.mp.
25	help adj3 seek$
26	exp help seeking behaviour/
27	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28	symptom$.mp.
29	sign$1.mp.
30	onset.mp.

#	Search Terms
31	notic$3.mp.
32	detect.mp.
33	aware$.mp.
34	recogni$.mp.
35	28 or 29 or 30 or 31 or 32 or 33 or 34
36	exp emotions/
37	exp anxiety/
38	exp attitude to health/
39	exp Attitude of Health Personnel/
40	exp attitude/
41	exp patient compliance/
42	exp social support/
43	exp health behavio?r
44	anx*4.mp.
45	attitude$.mp.
46	distress$.mp.
47	worr*3.mp.
48	concern$.mp.
49	embarrass$.mp.
50	discourag$.mp.
51	reassur$.mp.
52	emotion$.mp.
53	belie$.mp
54	perceive$.mp.
55	interpret$.mp.
56	access$.mp.
57	reason$.mp.
58	priorit$.mp.
59	percep$.mp.
60	cognit$.mp.
61	behav$.mp.
62	psychosocial.mp.

#	Search Terms
63	36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62
64	exp questionnaires/
65	exp psychometrics/
66	measur$.mp.
67	assess$.mp.
68	scale$.mp.
69	instrument$.mp.
70	survey$.mp.
71	quantitative$.mp.
72	64 or 65 or 66 or 67 or 68 or 69 or 70 or 71
73	1 and 13 and 27 and 35 and 63 and 72
74	limit 73 to yr="2004-2014"

Appendix 4: Search Strategy for CINAHL

#	**Search Terms**
1	MH “Neoplasms”
2	MH “Diagnosis, Delayed”
3	MH “Early Diagnosis”
4	MH “Early Detection of Cancer”
5	MH “Time Factors”
6	Wait*
7	Postpone*
8	Late*
9	duration
10	Interval*
11	Ignore*
12	Dismiss*
13	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14	MH “Primary Health Care”
15	MH “Health Services Accessibility”
16	MH “Health Services”
17	MH “Referral and Consultation”
18	MH “physicians”
19	Present*
20	Attend*
21	Consult*
22	sought
23	consider
24	MH “Help Seeking Behavior”
25	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26	Symptom*
27	Sign*
28	Onset*
29	Notic*
30	Detect*

#	Search Terms
31	Aware*
32	Recogni*
33	26 or 27 or 28 or 29 or 30 or 31 or 32
34	MH “emotions”
35	MH “anxiety”
36	MH “attitude to health”
37	MH “Attitude of Health Personnel”
38	MH “attitude”
39	MH “patient compliance”
40	MH “Support, Psychosocial”
41	anxious
42	anxiety
43	Attitude*
44	Distress*
45	Worr*
46	Concern*
47	Embarrass*
48	Discourage*
49	Reassure*
50	Emotion*
51	Belie*
52	Perceive*
53	Interpret*
54	Access*
55	Reason*
56	Priorit*
57	Percep*
58	Cognit*
59	Behav*
60	Psychosocial*
61	34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60
62	MH “questionnaires”

#	Search Terms
63	MH “psychometrics”
64	Measure*
65	Assess*
66	Scale*
67	Instrument*
68	Survey*
69	Quantitative*
70	62 or 63 or 64 or 65 or 66 or 67 or 68 or 69
71	1 and 13 and 25 and 33 and 61 and 70
72	limit 70 to yr="2004-2014"

Appendix 5: Search strategy for PsycINFO

#	Search Terms
1	exp Neoplasms/
2	exp Diagnosis/
3	exp Time Perspective/
4	wait$.mp
5	postpon$.mp.
6	late$.mp.
7	duration.mp.
8	interval$.mp.
9	ignore$.mp.
10	dismiss$.mp.
11	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12	exp Primary Health Care/
13	exp Health Care Delivery/
14	exp Health Care Service/
15	exp professional referral/
16	exp Client Attitudes/
17	exp physicians/
18	present$.mp.
19	attend$.mp.
20	consult$.mp.
21	sought.mp.
22	consider.mp.
23	help adj3 seek$
24	exp Health Care Seeking Behavio?r/
25	12 or 13 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26	symptom$.mp.
27	sign$1.mp.
28	onset.mp.
29	notic$3.mp.
30	detect.mp.

#	Search Terms
31	aware$.mp.
32	recogni$.mp.
33	26 or 27 or 28 or 29 or 30 or 31 or 32
34	exp emotions/
35	exp anxiety/
36	exp health attitudes/
37	exp health personnel attitudes /
38	exp attitudes/
39	exp health behavio?r/
40	exp Treatment Compliance
41	exp social support/
42	anx*4.mp.
43	attitude$.mp.
44	distress$.mp.
45	worr*3.mp.
46	concern$.mp.
47	embarrass$.mp.
48	discourag$.mp.
49	reassur$.mp.
50	emotion$.mp.
51	belie$.mp
52	perceive$.mp.
53	interpret$.mp.
54	access$.mp.
55	reason$.mp.
56	priorit$.mp.
57	percep$.mp.
58	cognit$.mp.
59	behav$.mp.
60	psychosocial.mp.
61	34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60
62	exp questionnaires/

#	Search Terms
63	exp psychometrics/
64	measur$.mp.
65	assess$.mp.
66	scale$.mp.
67	instrument$.mp.
68	survey$.mp.
69	quantitative$.mp.
70	62 or 63 or 64 or 65 or 66 or 67 or 68 or 69
71	1 and 11 and 25 and 33 and 61 and 70
72	limit 71 to yr="2004-2014"

Appendix 6: Search strategy for Web of Science

#	**Search Terms**
1	Neoplasm* OR Cancer OR Diagnosis OR Time OR Wait* OR Postpon* OR Late* OR Early OR Delay* OR Duration OR Interval* OR Ignore* OR Dismiss
2	Healthcare OR Physician OR Doctor OR Practitioner OR Refer* OR Consult* OR Access* OR Present* OR Attend* OR sought OR seek OR Help OR Consider
3	Symptom* OR Sign* OR Onset OR Notice* OR Noticing OR Detect* OR Aware* OR Recogni*
4	Emotion* OR Anxiety OR Anxious OR Attitude* OR Compliance OR Social OR Support OR Psychosocial OR Distress* OR Worr* OR Concern* OR Embarrass* OR Discourage* or Reassure* OR Belie* OR Perceive* OR Interpret* OR Access* OR Reason* OR Priorit* OR Percep* OR Cognit* OR Behav*
5	Questionnaire* OR Psychometric* OR Measure* OR Assess* OR Scale* OR Instrument* OR Survey* OR Quantitative*
6	1 AND 2 AND 3 AND 4 AND 5

[N.B. Search period defined by selecting the “TIMESPAN” option in the search menu]

Appendix 7: Data extraction form

Reviewer:	**Date:**

Inclusion criteria		
1) Does the study look at actual time to presentation (i.e. symptom appraisal and/or help-seeking behaviour) for [potential] symptoms of cancer?	Yes	No
2) Does the study look at the contributing psychosocial factors* that affect actual time to presentation for [potential] symptoms of cancer? **Psychosocial factors:* Emotional, cognitive and behavioural responses of the patient to the discovery of a symptom, social support/influences	Yes	No
3) Did the study collect quantitative data through primary research?	Yes	No

Study details	
1) Title	
2) Authors	
3) Year	
4) Journal	
5) Citation	

Study characteristics	
1) Aims	
2) Study design	☐ Cross-sectional ☐ Case -control ☐ Cohort ☐ Randomised Controlled Trial

Participant characteristics		
1) Sample Size		
2) Age		
3) Gender	Male(N):	Female (N):
4) Ethnic group		
5) Country		
6) Language		
7) Cancer type(s)		

Measurement			
1) How were the factors measured?	☐ Mixed methods ☐ Structured Interview ☐ Medical Records ☐ Self-administered questionnaire ☐ Other		
2) Do the authors provide a definition for appraisal, help-seeking and/or time to presentation?	☐ Yes ☐ No If yes, provide further details of definition(s) used:		
3) What factors in relation to symptom appraisal and/or help-seeking behaviour for [potential] symptoms of cancer did the measurement assess?	Provide further details:		
4) Items / questions used			
5) Validity	Appraisal: ☐ Face validity ☐ Content validity ☐ Criterion- related validity ☐ Construct validity	Help-seeking ☐ Face validity ☐ Content validity ☐ Criterion- related validity ☐ Construct validity	Time to presentation: ☐ Face validity ☐ Content validity ☐ Criterion- related validity ☐ Construct validity
6) Reliability	☐ Test-retest ☐ Internal Consistency (Cronbach's alpha =) ☐ Other ☐ No evidence	☐ Test-retest ☐ Internal Consistency (Cronbach's alpha =) ☐ Other ☐ No evidence	☐ Test-retest ☐ Internal Consistency (Cronbach's alpha =) ☐ Other ☐ No evidence

7) Has the measurement been used since the original study?	☐ Yes ☐ No If yes, provide further details:

Other	
1) References to follow up	

**N.B. Data on association between psychosocial factors and TTP were extracted separately following peer review advice*

Association between psychosocial factors and TTP	
Was the association between psychosocial factors and TTP reported?	☐ Yes ☐ No Provide further details:

Appendix 8: PaTH-Q Version One

The Pathways To Healthcare Questionnaire

Section 1 : Reasons for not visiting a Healthcare Professional

We are interested in learning why people wait before contacting a healthcare professional (e.g. doctor or nurse) after they have first noticed symptoms. Below are a list of reasons that may make people think they **do not** need to see a healthcare professional about their symptoms. Think back to when you first noticed your symptoms. Please indicate the extent to which the following reasons made you wait before deciding to see a healthcare professional.

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
At first, I thought I did not need to see a healthcare professional because…						
1.	I thought nothing was wrong	☐	☐	☐	☐	☐
2.	I was getting more symptoms	☐	☐	☐	☐	☐
3.	My symptoms did not change	☐	☐	☐	☐	☐
4.	I thought my symptoms would last a short time	☐	☐	☐	☐	☐
5.	I am often ill	☐	☐	☐	☐	☐
At first, I thought I did not need to see a healthcare professional because…						
6.	Most symptoms are harmless	☐	☐	☐	☐	☐
7.	My symptoms were getting better	☐	☐	☐	☐	☐
8.	My symptoms lasted for longer than I expected	☐	☐	☐	☐	☐
9.	I often get these symptoms	☐	☐	☐	☐	☐
10.	I was in a lot of pain	☐	☐	☐	☐	☐
At first, I thought I did not need to see a healthcare professional because…						
11.	I am generally a healthy person	☐	☐	☐	☐	☐
12.	My symptoms were coming and going	☐	☐	☐	☐	☐
13.	I was able to do my normal activities	☐	☐	☐	☐	☐
14.	My symptoms were similar to symptoms I had in the past	☐	☐	☐	☐	☐
15.	I had never experienced these symptoms before	☐	☐	☐	☐	☐

Section 1 : Reasons for not visiting a Healthcare Professional (continued…)

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
At first, I thought I did <u>not</u> need to see a healthcare professional because…					
16. I thought my symptoms were normal	☐	☐	☐	☐	☐
17. A friend or family member had similar symptoms which turned out to be signs of illness	☐	☐	☐	☐	☐
18. My symptoms were difficult to notice	☐	☐	☐	☐	☐
19. People at my age do not get this type of symptom	☐	☐	☐	☐	☐
20. I thought my symptoms would be temporary	☐	☐	☐	☐	☐
At first, I thought I did <u>not</u> need to see a healthcare professional because…					
21. My symptoms interfered with my daily life	☐	☐	☐	☐	☐
22. My symptoms were persistent	☐	☐	☐	☐	☐
23. I thought nothing needed to be done about my symptoms	☐	☐	☐	☐	☐
24. I was not able to get out of bed	☐	☐	☐	☐	☐
25. I thought my symptoms were just due to my age	☐	☐	☐	☐	☐
At first, I thought I did <u>not</u> need to see a healthcare professional because…					
26. My symptoms were similar to those I saw in a health campaign	☐	☐	☐	☐	☐
27. I did not expect to get this symptom at my age	☐	☐	☐	☐	☐
28. My symptoms were unexpected	☐	☐	☐	☐	☐
29. My symptoms were only mild	☐	☐	☐	☐	☐
30. My symptoms did not stop me from doing everyday activities	☐	☐	☐	☐	☐
At first, I thought I did <u>not</u> need to see a healthcare professional because…					
31. People at my age get this symptom	☐	☐	☐	☐	☐
32. Symptoms rarely get better on their own	☐	☐	☐	☐	☐
33. I knew what had triggered my symptoms	☐	☐	☐	☐	☐
34. My symptoms were alarming	☐	☐	☐	☐	☐
35. I could explain my symptoms	☐	☐	☐	☐	☐
36. I thought my symptoms were not serious	☐	☐	☐	☐	☐

Section 2 : Triggers to seeking help

We are interested in learning what makes people decide to see a healthcare professional (e.g. doctor or nurse). Think back to **before** you visited a doctor or nurse about your symptoms. Please indicate the extent to which the following triggers made you decide to see a healthcare professional. If you have visited a healthcare professional more than once about your symptoms, then answer the question about the first time you visited a healthcare professional about your symptoms.

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I thought I needed to see a healthcare professional because…						
1.	I thought something was wrong	☐	☐	☐	☐	☐
2.	I was getting more symptoms	☐	☐	☐	☐	☐
3.	My symptoms did not change	☐	☐	☐	☐	☐
4.	I thought my symptoms would last a short time	☐	☐	☐	☐	☐
5.	I am often ill	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
6.	Most symptoms are harmless	☐	☐	☐	☐	☐
7.	My symptoms were getting better	☐	☐	☐	☐	☐
8.	My symptoms lasted for longer than I expected	☐	☐	☐	☐	☐
9.	I often get these symptoms	☐	☐	☐	☐	☐
10.	I was in a lot of pain	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
11.	I am generally a healthy person	☐	☐	☐	☐	☐
12.	My symptoms were coming and going	☐	☐	☐	☐	☐
13.	I was able to do my normal activities	☐	☐	☐	☐	☐
14.	My symptoms were similar to symptoms I had in the past	☐	☐	☐	☐	☐
15.	I had never experienced these symptoms before	☐	☐	☐	☐	☐

Appendix 9: KCL Ethics Documentation (Study Three)

Kummer, Sonja

From: [redacted]
Sent: 20 January 2016 16:13
To: Kummer, Sonja
Subject: RE: Uncertain if ethical approval needed

Dear Sonja,

I can confirm that you wouldn't need KCL REC approval for the studies you plan to conduct.

Best wishes,

[redacted]

From: Kummer, Sonja
Sent: 20 January 2016 15:49
To: kcl - bdm
Subject: FW: Uncertain if ethical approval needed

Dear [redacted]

Further to our conversation earlier today please see below for a written confirmation that I will not require NHS approval. Can you please confirm again that I won't need KCL ethics either for both of the studies.

Thank you & best wishes
Sonja

From: [redacted]
Sent: 20 January 2016 15:23
To: Kummer, Sonja
Subject: RE: Ethical approval for Patient & Public Involvement

Hi Sonja,

That's correct for the PPI involvement in helping the design of the questionnaire you would not need REC approval, but when you have the questionnaire finalised and ready for use in the clinical setting you would need REC and R&D approval before you undertook the research/recruited participants.

Many thanks

[redacted]

[redacted]
Research & Development Governance Specialist
NIHR GSTFT/KCL Biomedical Research Centre
T: +44 (0)20 7188 7188 Ext: 54426| F: 0207 188 8330 |
T: [redacted] W: www.guysandstthomas.nhs.uk/

Guy's and St Thomas' and King's College London working together with our partners to deliver better health through research www.guysandstthomasbrc.nihr.ac.uk

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From: Kummer, Sonja [mailto:sonja.kummer@kcl.ac.uk]
Sent: 20 January 2016 14:00
To: [redacted]
Subject: Ethical approval for Patient & Public Involvement

Dear [redacted]

I am not sure if you can help me with this matter, but I already contacted NHS ethics about this and was informed that I should contact R&D in the first instance. I am a PhD student at King's College London, based at Guy's Hospital, and I would be grateful if you could provide me with guidance on whether NHS ethical approval is required prior to carrying out the below.

My PhD involves developing a questionnaire which is to be used with patients who have sought help for potential cancer symptoms in order to assess the factors that contributed to their decision to seek help. However, before using the questionnaire in an NHS patient setting I'd like to conduct interviews with members of the South East London Cancer Research Network's Patient and Public Involvement Group (SELCRN PPI Group) to identify any problematic questions or comprehension problems that individuals may have when they answer the questions/questionnaire. Essentially, the findings from the interviews with the SELCRN PPI Group will further inform my questionnaire development, and therefore my main PhD study (using the questionnaire in an NHS patient setting), as well as being written up as part of the PhD thesis and possibly presented in academic journals or at conferences.

I have read that ethical approval is not needed for the active involvement element of the research, (even when people are recruited via the NHS), where people are involved in planning or advising on research e.g. helping to develop a questionnaire. As such, can you reassure me that I will not require NHS ethical approval in this situation? Please let me know if you require any further information (i.e. a copy of the study protocol).

I would be grateful for your reply and look forward to hearing from you.

Kind Regards,

Sonja Kummer

Kind Regards,

Sonja Kummer

Sonja Kummer
PhD Researcher
Population and Patient Health, Social and Behavioural Sciences Unit
Dental Institute
King's College London
18th Floor
Tower Wing
Guy's Hospital
SE1 9RT
Email: sonja.kummer@kcl.ac.uk

From: [redacted]
Sent: 19 January 2016 09:41
To: Kummer, Sonja
Subject: FW: Uncertain if ethical approval needed

Dear Sonja,

Can you please clarify if the SE London Cancer Research Network is an NHS Group or NHS affiliated? If this is the case you would need to contact the HRA to find out if NHS REC approval is required. If this is not the case and the research isn't collecting any data to be used in their final report (i.e. this is background research to inform the study) then your research does not need ethical approval from us.

Best wishes,

[redacted]

From: Kummer, Sonja
Sent: 18 January 2016 10:30
To: kcl - bdm
Subject: RE: Uncertain if ethical approval needed

Dear [redacted]

Further to our telephone conversation on Friday please find attached the expert panel rating form I am planning to send to experts. The expert panel (academic researchers and GPs) will be given an expert rating form and asked to indicate whether they think the items in the questionnaire are relevant and whether any revisions should be made. Please note that the form might still be subject to a few format changes before sending it out to the panel, specifically as we are still deciding whether to send it out as a paper format or do an online survey. However. the questions (possibly barring some minor alterations to the instructions) should remain the same. If you require any further info (such as a study proposal) please let me know.

Best wishes
Sonja

From: Kummer, Sonja
Sent: 13 January 2016 11:52
To: kcl - bdm
Subject: Uncertain if ethical approval needed

Dear [redacted]

I am a PhD student at the Dental Institute and I wanted to enquire whether I will need ethical approval prior to carrying the two studies outlined below.

My PhD involves developing a questionnaire which is to be used with patients who have sought help for potential cancer symptoms in order to retrospectively assess the factors that contributed to their decision to seek help. However, before using it in a patient setting I'd like to conduct two studies: a content validity and face validity study. These two studies will help me to refine, remove and add items prior to final questionnaire preparation and administration.
I agree that this doesn't require approval.

For the content validity study, I will send the questionnaire to an expert panel (academic researchers and GPs) and ask them whether they think the items in the questionnaire are relevant and whether any revisions should be made. For the face validity study, I will carry out interviews with members of the South East London Cancer Research Network (so individuals who've had a cancer diagnosis) to identify any problematic questions or comprehension problems that they may have when they answer the questions/questionnaire.
I think we need them to clarify if the SE London Cancer Research Network is an NHS Group or NHS affiliated, in which case the researcher would need to contact the HRA to find out if NHS REC approval is required. If this is not the case and the research isn't collected any data to be used in their final report (i.e this is background research to inform the study) then this would not need ethical approval from us.

Also, please note that the questionnaire does not mention cancer (so as to minimise distress for those still awaiting a diagnosis and because we understand that the majority of people do not consider cancer when interpreting their symptoms)

I'd be really grateful for your help and look forward to hearing from you soon.

Best wishes
Sonja

Kind Regards,

Sonja Kummer

Sonja Kummer
PhD Researcher
Population and Patient Health, Social and Behavioural Sciences Unit
Dental Institute
King's College London
18th Floor
Tower Wing
Guy's Hospital
SE1 9RT
Email: sonja.kummer@kcl.ac.uk

Appendix 10: Expert Review Invitation Email (Content Validity; PaTH-Q Version One)

Kummer, Sonja

From: Kummer, Sonja
Sent: 02 March 2016 11:56
To: [redacted]
Subject: Expert Review Study Invitation

Dear [redacted]

I am a PhD student at King's College London [supervised by Dr Suzanne Scott (King's College London), Dr Fiona Walter (University of Cambridge) and Dr Joseph Chilcot (King's College London)] and have begun work on the development of a theory-based questionnaire that can be used with patients who have sought help for potential symptoms of cancer, in order to assess the factors that contributed to their decision to seek help. In particular, this questionnaire aims to assess the psychological biases in symptom perception that may heed or hasten the perceived need for care.

I am writing to ask if you would be willing to serve as an expert panel reviewer for this questionnaire. Your expertise in health psychology and early diagnosis would make your feedback most welcome. My hope is that this preliminary work to assess the content validity will support the need and appropriateness of the questionnaire.

If you agree to serve as an expert panel reviewer I will send you a reviewer package by mail. You would have one month to complete your feedback and return the package to me. The package will take approximately 30 minutes to complete. Please let me know if you are willing to assist me with this early work in instrument development.

I look forward to your expertise and feedback to guide this process.

If you would like any additional information prior to making a decision to serve as a reviewer, please do not hesitate to contact me.

Thank you for your time and consideration.

Sincerely,
Sonja Kummer

Sonja Kummer
PhD Researcher
Population and Patient Health, Social and Behavioural Sciences Unit
Dental Institute
King's College London
18th Floor
Tower Wing
Guy's Hospital
SE1 9RT
Email: sonja.kummer@kcl.ac.uk

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Appendix 11: Expert Review Cover Letter (Content Validity; PaTH-Q Version One)

Dental Institute
at Guy's, King's College
and St Thomas'
Hospitals

King's College London Dental Institute
Population and Patient Health Division
Floor 18, Tower Wing
Guy's Campus
London SE1 9RT
Telephone +44 (0)20 3299 3481

[Date]

Dear XXX,

Thank you for agreeing to participate as an expert panel reviewer.

Numerous studies have examined how psychosocial factors may affect time to presentation (the period of time between an individual's first detection of a change in their body and their first consultation with a healthcare professional) for a serious condition such as cancer. However, to date none of these studies have investigated how or whether psychological heuristics influence symptom interpretation and affect a person's time to presentation. Heuristics are rules of thumb that people may use to interpret symptoms and decide whether these symptoms require medical care.

In order to assess the influence of these heuristics we have developed a theoretically derived measure called the 'Pathways To Healthcare Questionnaire' (PaTH-Q). The PaTH-Q is a self-administered questionnaire which is to be used with patients who have sought help for potential cancer symptoms in order to retrospectively assess the factors that contributed to their decision to seek help. Although designed for use in early cancer diagnosis studies, the questionnaire does not mention cancer (so as to minimise distress for those still awaiting a diagnosis and because we understand that the majority of people do not consider cancer when interpreting their symptoms). Further, the questionnaire is generic in that is not intended for any specific cancer type. A copy of the draft questionnaire is included in this package.

As an expert panel reviewer, I am asking you to complete the expert rating form enclosed in this package which will require you to:

1) rate each item on its relevancy to the construct of heuristics;
2) rate each item on its clarity;
3) indicate whether an item should be deleted;
4) judge the overall comprehensiveness of the tool;
5) offer suggestions about revision, addition, or deletion of items that might facilitate refinement of the tool; and
6) indicate whether you think there are any constructs this instrument has missed.

Please complete your feedback by **[Date]** and return the package via the stamped pre-paid envelope.

You may be invited to take part in a second round if necessary, to explore any additional instrument issues. If you do not wish to be invited to take part in a second round you can let us know at the end of the reviewer package.

If you have any questions, please do not hesitate to contact me (sonja.kummer@kcl.ac.uk)

Thank you for your time and consideration.

Yours sincerely

[redacted]

Sonja Kummer

Appendix 12: Expert Review Rating Form (Content Validity; PaTH-Q Version One)

Expert Reviewer Rating Form

Instructions:

The 'Pathways To Healthcare Questionnaire' (PaTH-Q) consists of two sections.

Section 1: In this section we are interested in learning why people wait before contacting a healthcare professional (e.g. doctor or nurse) after they have first noticed symptoms.

Section 2: In this section we are interested in learning what makes people decide to see a healthcare professional (e.g. doctor or nurse) after they have first noticed symptoms.

For the expert panel task, items relating to each heuristic have been grouped together (they are mixed up in the actual questionnaire). The definition of each heuristic is provided at the top of each page and the items are on the left-hand-side of the page. There are four items for each heuristic, one of which is reverse coded. Please read the definition of the heuristic, and then rate the items **using the shaded expert rating form** on the right-hand-side of the page.

Please rate each item as follows:

- The level of representativeness on a scale of 1 – 4.
- The level of clarity for each item, on a scale of 1 – 4.
- Whether or not an item should be deleted.

Space is provided for you at the end of each section to make any additional comments.

'Rate of Change' Heuristic

The following questions aim to assess the influence of the **'rate of change'** rule/heuristic. This heuristic states that:
Symptoms that are worsening, unstable, or increasing in number, and symptoms that have a sudden rather than gradual onset, can indicate illness and provide motivation to seek help promptly. In comparison, symptoms that are getting better/improving, fluctuating, stable, or decreasing in number, can indicate absence of illness and reduce motivation to seek help promptly.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
My symptoms were getting better						1 2 3 4	1 2 3 4	Yes / No
My symptoms were coming and going						1 2 3 4	1 2 3 4	Yes / No
My symptoms did not change						1 2 3 4	1 2 3 4	Yes / No
I was getting more symptoms						1 2 3 4	1 2 3 4	Yes / No

SECTION 2:

I thought I needed to see a healthcare professional because…								
My symptoms were getting better						1 2 3 4	1 2 3 4	Yes / No
My symptoms were coming and going						1 2 3 4	1 2 3 4	Yes / No
My symptoms did not change						1 2 3 4	1 2 3 4	Yes / No
I was getting more symptoms						1 2 3 4	1 2 3 4	Yes / No

ADDITIONAL COMMENTS/ITEMS:

'Age-illness' Heuristic

The following questions aim to assess the influence of the **'age-illness'** rule/heuristic. This heuristic states that:
As individuals grow older, they increasingly attribute sensations to the ageing process rather than to illness.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
People at my age get this symptom						1 2 3 4	1 2 3 4	Yes / No
I thought my symptoms were just due to my age						1 2 3 4	1 2 3 4	Yes / No
People at my age do not get this type of symptom						1 2 3 4	1 2 3 4	Yes / No
I did not expect to get this symptom at my age						1 2 3 4	1 2 3 4	Yes / No

SECTION 2:

I thought I needed to see a healthcare professional because…								
People at my age get this symptom						1 2 3 4	1 2 3 4	Yes / No
I thought my symptoms were just due to my age						1 2 3 4	1 2 3 4	Yes / No
People at my age do not get this type of symptom						1 2 3 4	1 2 3 4	Yes / No
I did not expect to get this symptom at my age						1 2 3 4	1 2 3 4	Yes / No

ADDITIONAL COMMENTS/ITEMS:

'Novelty' Heuristic

The following questions aim to assess the influence of the **'novelty'** rule/heuristic. This heuristic states that:
Symptoms that are new, different, or incongruent (unexpected) with underlying schema rather than familiar, common, or similar to a co-existing chronic illness can be a key motivator to seek help.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form** **Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
I often get these symptoms						1 2 3 4	1 2 3 4	Yes / No
My symptoms were similar to symptoms I had in the past						1 2 3 4	1 2 3 4	Yes / No
I had never experienced these symptoms						1 2 3 4	1 2 3 4	Yes / No
My symptoms were unexpected						1 2 3 4	1 2 3 4	Yes / No

SECTION 2:

I thought I needed to see a healthcare professional because…								
I often get these symptoms						1 2 3 4	1 2 3 4	Yes / No
My symptoms were similar to symptoms I had in the past						1 2 3 4	1 2 3 4	Yes / No
I had never experienced these symptoms						1 2 3 4	1 2 3 4	Yes / No
My symptoms were unexpected						1 2 3 4	1 2 3 4	Yes / No

ADDITIONAL COMMENTS/ITEMS:

'Pattern' Heuristic

The following questions aim to assess the influence of the **'pattern'** rule/heuristic. This heuristic states that:
Compared to symptoms that are striking, severe or extreme, symptoms that are diffuse, mild, ambiguous or vague lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Thus, diffuse, mild, ambiguous or vague symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care

						Expert Reviewer Rating Form Please circle your response for each item		
SECTION 1:						**Representativeness**	**Clarity**	**Inclusion**
At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
I was in a lot of pain						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were alarming						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were only mild						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were difficult to notice						**1 2 3 4**	**1 2 3 4**	**Yes / No**
SECTION 2:								
I thought I needed to see a healthcare professional because…								
I was in a lot of pain						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were alarming						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were only mild						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were difficult to notice						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Duration' Heuristic

The following questions aim to assess the influence of the **'duration'** rule/heuristic. This heuristic states that:
Symptoms that are persistent or prolonged (compared to previous experience or expectations), rather than short lived or intermittent, can indicate a level of seriousness, which in turn, can be a reason for urgently seeking help.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
I thought my symptoms were temporary						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought my symptoms would last a short time						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms lasted for longer than I expected						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were persistent						**1 2 3 4**	**1 2 3 4**	**Yes / No**

SECTION 2:

I thought I needed to see a healthcare professional because...								
I thought my symptoms were temporary						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought my symptoms would last a short time						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms lasted for longer than I expected						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were persistent						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Symmetry' Heuristic

The following questions aim to assess the influence of the **'symmetry'** rule/heuristic. The heuristic states that:
Detection of bodily changes stimulates labelling, attributing a cause, explanation or reason for the change.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
A friend or family member had similar symptoms which turned out to be signs of illness						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were similar to those I saw in a health campaign						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I could explain my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I knew what had triggered my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**

SECTION 2:

I thought I needed to see a healthcare professional because…								
A friend or family member had similar symptoms which turned out to be signs of illness						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were similar to those I saw in a health campaign						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I could explain my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I knew what had triggered my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Optimistic bias' Heuristic

The following questions aim to assess the influence of the **'optimistic bias'** rule/heuristic. This heuristic states that:
Individuals have a generally optimistic bias in that their interpretations, in keeping with previous experience, and will tend to make innocuous explanations rather than those that are life threatening.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form** **Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
I am generally a healthy person						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I am often ill						**1 2 3 4**	**1 2 3 4**	**Yes / No**
Most symptoms are harmless						**1 2 3 4**	**1 2 3 4**	**Yes / No**
Symptoms rarely get better on their own						**1 2 3 4**	**1 2 3 4**	**Yes / No**

SECTION 2:

I thought I needed to see a healthcare professional because…								
I am generally a healthy person						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I am often ill						**1 2 3 4**	**1 2 3 4**	**Yes / No**
Most symptoms are harmless						**1 2 3 4**	**1 2 3 4**	**Yes / No**
Symptoms rarely get better on their own						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Severity' Heuristic

The following questions aim to assess the influence of the **'severity'** rule/heuristic. This heuristic states that:
Symptoms that disrupt functioning indicate the presence of illness and/or the need for care whereas those that allow normal functioning will reduce motivation to seek help.

SECTION 1:

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form** **Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
My symptoms did not stop me from doing everyday activities						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I was able to do my normal activities						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I was not able to get out of bed						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms interfered with my daily life						**1 2 3 4**	**1 2 3 4**	**Yes / No**

SECTION 2:

I thought I needed to see a healthcare professional because…								
My symptoms did not stop me from doing everyday activities						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I was able to do my normal activities						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I was not able to get out of bed						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms interfered with my daily life						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Reasons to consider seeking help'

The following questions aim to assess the **influence of 'Reasons to consider seeking help'.** The definition states that:
The time point at which an individual believes they have a motive to consult a Healthcare Professional (HCP) about their symptoms and thus consider seeking help from a HCP. Reasons for discussing symptoms with a HCP are likely to be due to cognitive factors (e.g. beliefs about symptoms, something is wrong / serious), consequences of symptoms (e.g. interference of symptoms with one's ability to work), perceived inability to cope with symptoms (e.g. persistence, symptom salience, failure to self-medicate) and emotional factors (e.g. anxiety, concern, need for reassurance).

I thought I needed to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form Please circle your response for each item** **Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
I thought something was wrong						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were not normal						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought my symptoms were serious						**1 2 3 4**	**1 2 3 4**	**Yes / No**
Something needed to be done about my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Reasons not to consider seeking help'

The following questions aim to assess the influence of '**Reasons not to consider seeking help'.** The definition states that:
The time point at which an individual believes they do not have a motive to consult a Healthcare Professional (HCP) about their symptoms and thus do not consider seeking help from a HCP. Reasons for not discussing symptoms with a HCP are likely to be due to cognitive factors (e.g. beliefs about symptoms, nothing is wrong / serious), no consequences of symptoms (e.g. no interference of symptoms with one's ability to work), perceived ability to cope with symptoms (e.g. persistence, symptom salience, aptitude to self-medicate), emotional factors (e.g. no anxiety, no concern, no need for reassurance).

At first, I thought I did not need to see a healthcare professional because…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Expert Reviewer Rating Form Please circle your response for each item**		
						Representativeness	**Clarity**	**Inclusion**
						1 = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
I thought nothing was wrong						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were normal						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought my symptoms were not serious						**1 2 3 4**	**1 2 3 4**	**Yes / No**
Nothing needed to be done about my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

Appendix 13: PaTH-Q Version Two

THE PATHWAYS TO HEALTHCARE QUESTIONNAIRE

Section 1 : Reasons for not visiting a Healthcare Professional

We are interested in symptoms which you think are related to your recent referral to hospital. The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it. Please give an exact date if you can. Otherwise please give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

1. What was the first thing or symptom(s) you noticed that made you think that something might be wrong?

2. When did you first notice this?

OR

Exact Date *dd/mm/yyyy*

Estimate

3. Think back to when you first noticed your symptoms. Please indicate the extent to which the following reasons made you wait before deciding to see a healthcare professional.

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
At first, I thought I <u>did not</u> need to see a healthcare professional because...						
1	My symptoms were getting better	☐	☐	☐	☐	☐
2	I could still do my everyday activities	☐	☐	☐	☐	☐
3	My symptoms were normal	☐	☐	☐	☐	☐
4	I did not get more symptoms	☐	☐	☐	☐	☐
5	I thought my symptoms were due to age rather than illness	☐	☐	☐	☐	☐
At first, I thought I <u>did not</u> need to see a healthcare professional because...						
6	I was still able to get out of bed	☐	☐	☐	☐	☐
7	Symptoms often get better on their own	☐	☐	☐	☐	☐
8	I often get these symptoms	☐	☐	☐	☐	☐
9	People at my age do get this type of symptom	☐	☐	☐	☐	☐

Section 1 : Reasons for not visiting a Healthcare Professional *(continued…)*

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
At first, I thought I <u>did not</u> need to see a healthcare professional because…						
10	My symptoms started slowly	☐	☐	☐	☐	☐
11	It is normal for someone like me to get this symptom	☐	☐	☐	☐	☐
12	I thought my symptoms were temporary	☐	☐	☐	☐	☐
13	I was still able to move	☐	☐	☐	☐	☐
14	My symptoms were similar to symptoms I had in the past	☐	☐	☐	☐	☐
At first, I thought I <u>did not</u> need to see a healthcare professional because…						
15	My symptoms changed slowly or not at all	☐	☐	☐	☐	☐
16	I am rarely ill	☐	☐	☐	☐	☐
17	I was in no pain	☐	☐	☐	☐	☐
18	I knew what had triggered my symptoms	☐	☐	☐	☐	☐
19	My symptoms were only mild	☐	☐	☐	☐	☐
At first, I thought I <u>did not</u> need to see a healthcare professional because…						
20	My symptoms were difficult to notice	☐	☐	☐	☐	☐
21	My symptoms are common	☐	☐	☐	☐	☐
22	I thought my symptoms would get better on their own	☐	☐	☐	☐	☐
23	A friend or family member had similar symptoms which were not signs of illness	☐	☐	☐	☐	☐
24	I thought my symptoms would come and go	☐	☐	☐	☐	☐
At first, I thought I <u>did not</u> need to see a healthcare professional because…						
25	I expected to get this type of symptom at my age	☐	☐	☐	☐	☐
26	I thought my symptoms would be short lived	☐	☐	☐	☐	☐
27	My symptoms were different to those I saw in a health campaign	☐	☐	☐	☐	☐
28	I understood my symptoms	☐	☐	☐	☐	☐
29	Nothing needed to be done about my symptoms	☐	☐	☐	☐	☐

Section 1 : Reasons for not visiting a Healthcare Professional *(continued…)*

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
At first, I thought I <u>did not</u> need to see a healthcare professional because…						
30	I am generally a healthy person	☐	☐	☐	☐	☐
31	My symptoms were vague	☐	☐	☐	☐	☐
32	Most symptoms are harmless	☐	☐	☐	☐	☐
33	I was still able to eat	☐	☐	☐	☐	☐
At first, I thought I <u>did not</u> need to see a healthcare professional because…						
34	I thought nothing was wrong	☐	☐	☐	☐	☐
35	I expected to have these symptoms	☐	☐	☐	☐	☐
36	I thought my symptoms were not serious	☐	☐	☐	☐	☐

Section 2 : Triggers to seeking help

Questions in this section may look similar to questions you answered before. It is still important to fill in these questions, as now the questions are about what makes people decide to see a healthcare professional (e.g. doctor or nurse). Think back to **before** you visited a doctor or nurse about your symptoms.

1. When did you **first think** about telling your GP or nurse about your symptom?

Exact Date
dd/mm/yyyy

Estimated time after first noticing symptoms
..... Day(s)
..... Week(s)
.....Month(s)

2. When did you **first tell** your GP or nurse about your symptom(s)?

Exact Date
dd/mm/yyyy

OR

Estimated time after first noticing symptoms
..... Day(s)
..... Week(s)
.....Month(s)

3. Please indicate the extent to which the following triggers made you decide to see a healthcare professional. If you have visited a healthcare professional more than once about your symptoms, then answer the question about the first time you visited a healthcare professional about your symptoms.

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I thought I needed to see a healthcare professional because…						
1	My symptoms were getting worse	☐	☐	☐	☐	☐
2	I could not do my everyday activities	☐	☐	☐	☐	☐
3	My symptoms were not normal	☐	☐	☐	☐	☐
4	I got more symptoms	☐	☐	☐	☐	☐
5	I thought my symptoms were due to illness rather than age	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
6	I was unable to get out of bed	☐	☐	☐	☐	☐
7	Symptoms rarely get better on their own	☐	☐	☐	☐	☐
8	I rarely get these symptoms	☐	☐	☐	☐	☐
9	People at my age do not get this type of symptom	☐	☐	☐	☐	☐

Section 2 : Triggers to seeking help *(continued…)*

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I thought I needed to see a healthcare professional because…						
10	My symptoms started suddenly	☐	☐	☐	☐	☐
11	It is not normal for someone like me to get this symptom	☐	☐	☐	☐	☐
12	I thought my symptoms were persistent	☐	☐	☐	☐	☐
13	I was unable to move	☐	☐	☐	☐	☐
14	My symptoms were different to symptoms I have had in the past	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
15	My symptoms changed quickly	☐	☐	☐	☐	☐
16	I am often ill	☐	☐	☐	☐	☐
17	I was in pain	☐	☐	☐	☐	☐
18	I did not know what had triggered my symptoms	☐	☐	☐	☐	☐
19	My symptoms were not mild	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
20	My symptoms were easy to notice	☐	☐	☐	☐	☐
21	My symptoms were unusual	☐	☐	☐	☐	☐
22	I thought my symptoms were not getting better on their own	☐	☐	☐	☐	☐
23	A friend or family member had similar symptoms which turned out to be signs of illness	☐	☐	☐	☐	☐
24	I thought my symptoms should have been gone by then	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
25	I did not expect to get this symptom at my age	☐	☐	☐	☐	☐
26	I thought my symptoms would last a long time	☐	☐	☐	☐	☐
27	My symptoms were similar to those I saw in a health campaign	☐	☐	☐	☐	☐
28	I could not understand my symptoms	☐	☐	☐	☐	☐
29	Something needed to be done about my symptoms	☐	☐	☐	☐	☐

Section 2 : Triggers to seeking help *(continued…)*

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I thought I needed to see a healthcare professional because…						
30	My general health is not good	☐	☐	☐	☐	☐
31	My symptoms were striking	☐	☐	☐	☐	☐
32	Most symptoms are a sign of illness	☐	☐	☐	☐	☐
33	I was unable to eat	☐	☐	☐	☐	☐
I thought I needed to see a healthcare professional because…						
34	I thought something was wrong	☐	☐	☐	☐	☐
35	I did not expect to have these symptoms	☐	☐	☐	☐	☐
36	I thought my symptoms were serious	☐	☐	☐	☐	☐

Appendix 14: 'Think Aloud' Task Invitation (Face Validity; PaTH-Q Version Two)

Dental Institute
at Guy's, King's College
and St Thomas'
Hospitals

King's College London Dental Institute
Population and Patient Health Division
Floor 18, Tower Wing
Guy's Campus
London SE1 9RT
Telephone +44 (0)20 3299 3481

KING'S College LONDON

Dear Sir/Madam,

I am contacting you following my presentation on the "Development of the Pathways to Healthcare Questionnaire" at the SELCRP meeting that took place on May 27th 2016 to enquire if you would like to assist us with our research study.

You will have been forwarded a detailed information sheet about the study with this letter, which gives further details about the study and answers some of the questions you may have. Once you have read this through carefully and thought things over, please let me know if you have any further questions about this study, or whether or not you are interested in assisting us with this important research by emailing me at **sonja.kummer@kcl.ac.uk**.

Yours sincerely,

[redacted]

Sonja Kummer

Appendix 15: 'Think Aloud' Task Information Sheet (Face Validity; PaTH-Q Version Two)

KING'S College LONDON

Participant Information Sheet

Development of the Pathways to Healthcare Questionnaire (PaTH-Q). A face validity study.

We would like to invite you to participate in this research project. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. **Please ask us if there is anything that is not clear or you would like more information.**

Details of the study

We have recently designed a questionnaire to find out about how people decide to see a healthcare professional (e.g. doctor or nurse) after they have noticed [potential] symptoms of cancer. Before we ask lots of patients to complete the questionnaire, we want to make sure the questions make sense. Our study aims to identify any problems that people may have when they complete the questionnaire. For example, we will be exploring whether people have problems in understanding, answering or interpreting the questions in the questionnaire.

Who we are looking for

We are looking for participants aged 18 and over who have had a cancer diagnosis (currently or in the past).

Do you have to take part?

No, it is completely up to you. If you decide you would like to participate, then you will be given this information sheet to keep.

What will happen if you decide to take part

If you decide to participate, we will ask you to complete our new questionnaire and 'think aloud' as you do so. This means that we want you to tell us everything that you are thinking as you read the instructions, each question and decide how to answer it. We would like you to talk aloud constantly. We do not want you to plan out what you say or try to explain what you are saying. We will also collect some information about yourself (such as type of cancer, time since diagnosis) so that we can get an idea about the people who have taken part in this study. The 'think aloud' process will be audio recorded, subject to your permission.

The whole process should take around 45 minutes and we would like to offer you a £30 voucher to reimburse you for your time, as well as reimbursing any potential travel fees.

It is important to know:

- It is up to you to decide whether or not to take part.
- If you choose not to participate it will involve no penalty or loss of benefits to which you are otherwise entitled.

- If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form.
- If you decide to take part you are still free to withdraw at any time and without giving a reason.

Benefits to participating

Although there will be no immediate benefit to you to participating, we hope that you will find it rewarding to participate in research that could help us find out more about how people decide to see a healthcare professional after they have noticed [potential] symptoms of cancer.

Finally, we will provide you with a copy of the final report once we have finished the research if you wish to have one.

Potential risks

We understand that this can be a sensitive topic and talking or reading about it may cause some distress.

If you feel upset, you can immediately withdraw from the study. In addition, the researcher can advise you where you can seek help, and you can take a card which details sources of help.

Confidentiality

Your participation in the study will be kept strictly confidential and all information that you give will be anonymised so that others will not be able to identify you from it. The information will be stored securely and will not be passed on to anybody outside the research team. The audio recordings of the 'think aloud' process will be transcribed (written out) and once this is done the tapes will be deleted.

The data obtained from the study will be kept securely at King's College London for 7 years. After 7 years, all the information will be securely destroyed.

What will happen if you do not want to be part of the study anymore?

If you change your mind, you are fee to withdraw at any time without giving a reason. If you decide you do not want to take part in the study after the 'think aloud' process is complete, you are free to withdraw at any time before the final report is written up without giving a reason. Any data collected from you will be removed from the study. The final report for the study is to be written up by the end of September 2016 and you have all this time to withdraw from the study.

What will happen to the results?

The results will be used to help us to further refine the 'Pathways to Healthcare Questionnaire' (PaTH-Q). The results will be written up as part of a PhD. We also hope to publish the results in an academic journal. You can get a copy of the final report from Sonja Kummer (sonja.kummer@kcl.ac.uk).

Who is organising and funding the research?

The study is being undertaken by a postgraduate research student at the Dental Institute, King's College London towards a doctoral (PhD) degree. The research team includes:

- Miss Sonja Kummer (King's College London) – Postgraduate Research student and Principal Investigator
- Dr Suzanne Scott (King's College London) – Senior Lecturer in Health Psychology and Supervisor
- Dr Fiona Walter (University of Cambridge) - Principal Researcher in Primary Care Cancer Research and Supervisor
- Dr Joseph Chilcot (King's College London) – Lecturer in Health Psychology and Supervisor

This study is funded by King's College London, Dental Institute.

Contact details for further information

If you have any questions or would like to obtain further information about this study please contact:

Sonja Kummer
Dental Institute, King's College London
18th Floor, Tower Wing
Guy's Hospital
Great Maze Pond
SE1 9RT
sonja.kummer@kcl.ac.uk

To receive independent advice about taking part in this research study or if it has harmed you in any way you can contact King's College London using the details below for further advice or information:

Dr Suzanne Scott
Senior Lecturer
Dental Institute, King's College London
18th Floor, Tower Wing
Guy's Hospital
Great Maze Pond
SE1 9RT
suzanne.scott@kcl.ac.uk

Appendix 16: 'Think Aloud' Task Information Sheet (Face Validity; PaTH-Q Version Three)

KING'S College LONDON

Participant Information Sheet

Development of the Pathways to Healthcare Questionnaire (PaTH-Q). A face validity study.

We would like to invite you to participate in this research project. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. **Please ask us if there is anything that is not clear or you would like more information.**

Details of the study

We have recently developed a questionnaire that aims to find out about how people decide to see a healthcare professional (e.g. doctor or nurse) after they have noticed any symptoms. Before we ask lots of people to complete the questionnaire, we want to make sure the questionnaire makes sense. Our study aims to identify any problems that people may have when they complete the questionnaire. For example, we will be exploring whether people have problems in understanding, answering or interpreting the questions in the questionnaire.

Who we are looking for

We are looking for participants aged 18 and over who went to see their healthcare professional about any symptoms they experienced within the last 6 months.

Do you have to take part?

No, it is completely up to you. If you decide you would like to participate, then you will be given this information sheet to keep.

What will happen if you decide to take part

If you decide to participate, we will ask you to complete our new questionnaire and 'think aloud' as you do so. This means that we want you to tell us everything that you are thinking as you read the instructions, each question and decide how to answer it. We would like you to talk aloud constantly. We do not want you to plan out what you say or try to explain what you are saying. We will also collect some information about yourself (such as age, gender) so that we can get an idea about the people who have taken part in this study. The **'think aloud' process** will be audio recorded, subject to your permission.

The whole process should take around 30 minutes and we would like to offer you a £30 voucher to reimburse you for your time, as well as reimbursing any potential travel fees.

It is important to know:

- It is up to you to decide whether or not to take part.
- If you choose not to participate it will involve no penalty or loss of benefits to which you are otherwise entitled.
- If you decide to take part you will be given this information sheet to keep.
- If you decide to take part you are still free to withdraw at any time and without giving a reason.

Benefits to participating

Although there will be no immediate benefit to you to participating, we hope that you will find it rewarding to participate in research that could help us find out more about how people decide to see a healthcare professional after they have noticed any symptoms.

Finally, we will provide you with a copy of the final report once we have finished the research if you wish to have one.

Potential risks

We understand that this can be a sensitive topic and talking or reading about it may cause some distress.

If you feel upset, you can immediately withdraw from the study. In addition, the researcher can advise you where you can seek help, and you can take a card which details sources of help.

Confidentiality

Your participation in the study will be kept strictly confidential and all information that you give will be anonymised so that others will not be able to identify you from it. The information will be stored securely and will not be passed on to anybody outside the research team. The audio recordings of the 'think aloud' process will be transcribed (written out) and once this is done the tapes will be deleted.

The data obtained from the study will be kept securely at King's College London for 7 years. After 7 years, all the information will be securely destroyed.

What will happen if you do not want to be part of the study anymore?

If you change your mind, you are fee to withdraw at any time without giving a reason. If you decide you do not want to take part in the study after the 'think aloud' process is complete, you are free to withdraw at any time before the final report is written up without giving a reason. Any data collected from you will be removed from the study. The final report for the study is to be written up by the end of September 2016 and you have all this time to withdraw from the study.

What will happen to the results?

The results will be used to help us to further refine the 'Pathways to Healthcare Questionnaire' (PaTH-Q). The results will be written up as part of a PhD. We also hope to publish the results in an academic journal. You can get a copy of the final report from Sonja Kummer (sonja.kummer@kcl.ac.uk).

Who is organising and funding the research?

The study is being undertaken by a postgraduate research student at the Dental Institute, King's College London towards a doctoral (PhD) degree. The research team includes:

- Miss Sonja Kummer (King's College London) – Postgraduate Research student and Principal Investigator
- Dr Suzanne Scott (King's College London) – Senior Lecturer in Health Psychology and Supervisor
- Dr Fiona Walter (University of Cambridge) - Principal Researcher in Primary Care Cancer Research and Supervisor
- Dr Joseph Chilcot (King's College London) – Lecturer in Health Psychology and Supervisor

This study is funded by King's College London, Dental Institute.

Contact details for further information

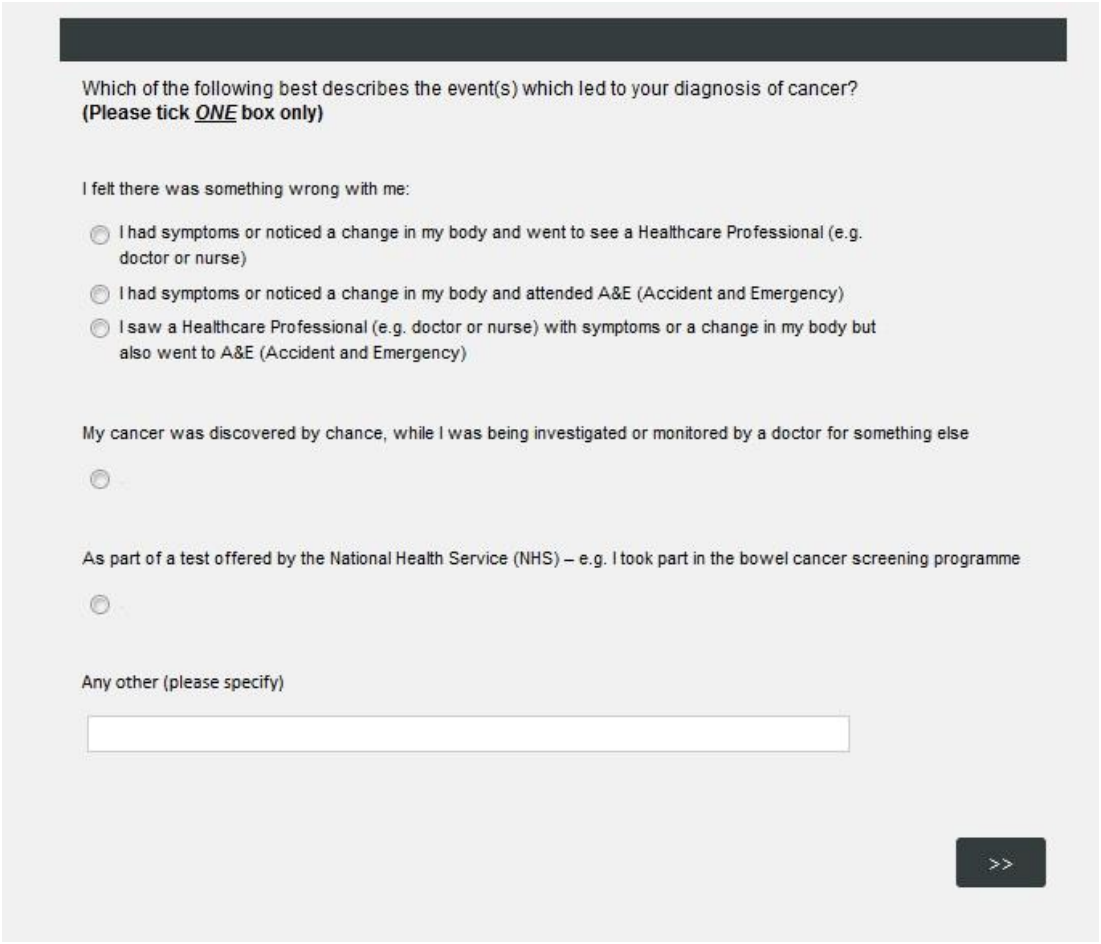
If you have any questions or would like to obtain further information about this study please contact:

Sonja Kummer
Dental Institute, King's College London
18th Floor, Tower Wing
Guy's Hospital
Great Maze Pond
SE1 9RT
sonja.kummer@kcl.ac.uk

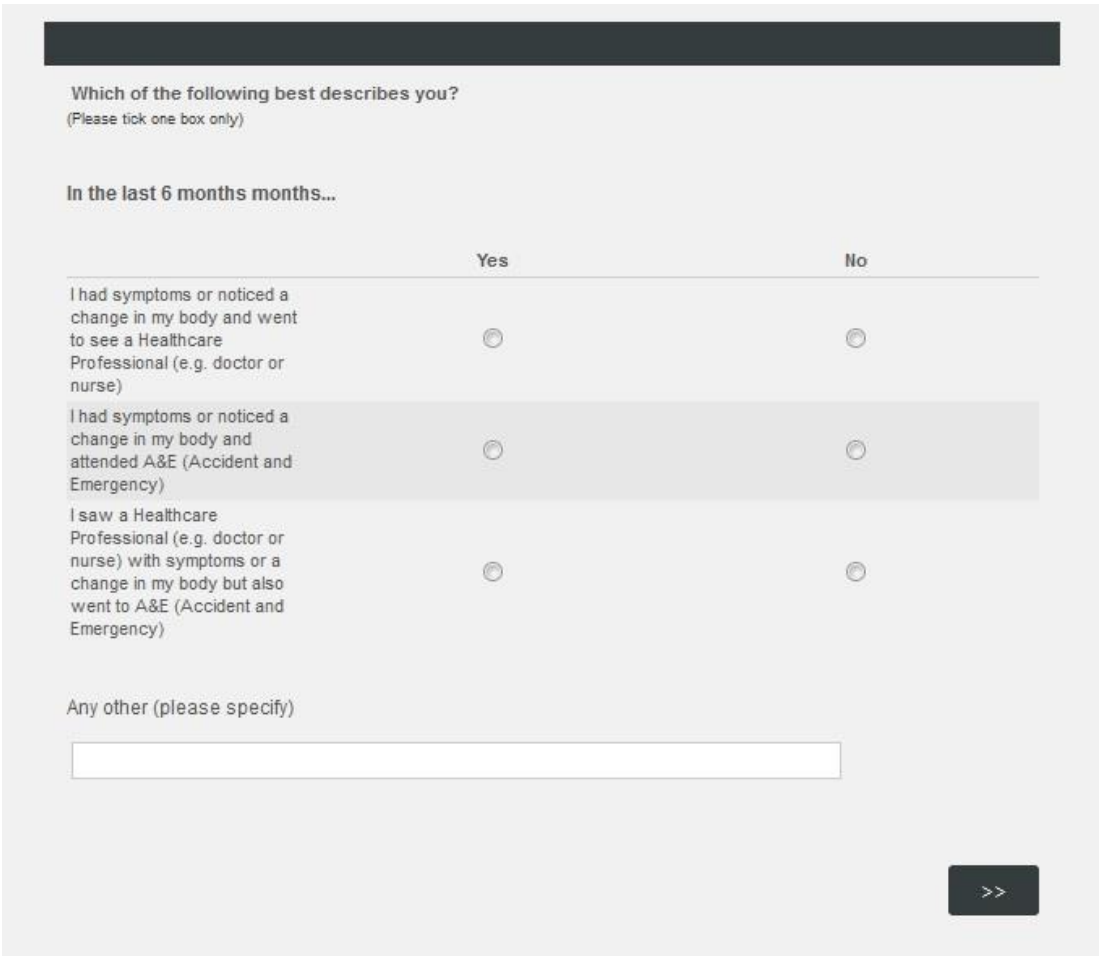
To receive independent advice about taking part in this research study or if it has harmed you in any way you can contact King's College London using the details below for further advice or information:

Dr Suzanne Scott
Senior Lecturer
Dental Institute, King's College London
18th Floor, Tower Wing
Guy's Hospital
Great Maze Pond
SE1 9RT
suzanne.scott@kcl.ac.uk

Appendix 17: 'Think Aloud' Task: Eligibility Assessment (Face Validity; PaTH-Q Version Two)



Appendix 18: 'Think Aloud' Task: Eligibility Assessment (Face Validity; PaTH-Q Version Three)



Which of the following best describes you?
(Please tick one box only)

In the last 6 months months...

	Yes	No
I had symptoms or noticed a change in my body and went to see a Healthcare Professional (e.g. doctor or nurse)	○	○
I had symptoms or noticed a change in my body and attended A&E (Accident and Emergency)	○	○
I saw a Healthcare Professional (e.g. doctor or nurse) with symptoms or a change in my body but also went to A&E (Accident and Emergency)	○	○

Any other (please specify)

>>

Appendix 19: PaTH-Q Version Three

THE PATHWAYS TO HEALTHCARE QUESTIONNAIRE

We are interested in symptoms which you think are related to your recent referral to hospital. The following questions are about when you first noticed a symptom. Please give an exact date if you can. Otherwise please give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

A) What was the first thing or symptom(s) you noticed that made you think that something might be wrong?

B) When did you first notice this?

Exact date: *dd/mm/yyyy*

OR

Estimate:

C) Think back to the time when you first noticed your symptom(s). Please indicate the extent to which you agree with the following statements.

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	At the start…					
1	My symptoms started suddenly	☐	☐	☐	☐	☐
2	My symptoms lasted longer than I expected	☐	☐	☐	☐	☐
3	I was unable to move	☐	☐	☐	☐	☐
4	I thought most symptoms are a sign of illness	☐	☐	☐	☐	☐
5	I got more and more symptoms	☐	☐	☐	☐	☐
6	My symptoms seemed to get better	☐	☐	☐	☐	☐
7	My symptoms were vague	☐	☐	☐	☐	☐
8	I was still able to get out of bed	☐	☐	☐	☐	☐
9	I was in pain	☐	☐	☐	☐	☐
10	I did not know what had triggered my symptoms	☐	☐	☐	☐	☐

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	At the start…					
11	I thought people at my age do not get this type of symptom	☐	☐	☐	☐	☐
12	I thought my symptoms would get better on their own	☐	☐	☐	☐	☐
13	I thought it is normal for someone like me to get this symptom	☐	☐	☐	☐	☐
14	My symptoms changed slowly or not at all	☐	☐	☐	☐	☐
15	My symptoms were coming and going	☐	☐	☐	☐	☐
16	My symptoms were similar to symptoms I had in the past	☐	☐	☐	☐	☐
17	I did not expect to have these symptoms	☐	☐	☐	☐	☐
18	I thought my symptoms were common	☐	☐	☐	☐	☐
19	I was unable to eat	☐	☐	☐	☐	☐
20	I understood my symptoms	☐	☐	☐	☐	☐
21	My symptoms were easy to notice	☐	☐	☐	☐	☐
22	I could still do my everyday activities	☐	☐	☐	☐	☐
23	My symptoms were striking	☐	☐	☐	☐	☐
24	I thought my symptoms were just due to age rather than illness	☐	☐	☐	☐	☐
25	I thought my symptoms would be short lived	☐	☐	☐	☐	☐
26	My symptoms seemed unusual	☐	☐	☐	☐	☐
27	My symptoms were getting worse	☐	☐	☐	☐	☐
28	My symptoms were persistent	☐	☐	☐	☐	☐
29	A friend or family member had similar symptoms which turned out to be signs of illness	☐	☐	☐	☐	☐
30	I thought something needed to be done about my symptoms	☐	☐	☐	☐	☐

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	At the start…					
31	It was unlikely to be a sign of illness, because I am generally a healthy person	☐	☐	☐	☐	☐
32	I did not expect to get this symptom at my age	☐	☐	☐	☐	☐
33	My symptoms were only mild	☐	☐	☐	☐	☐
34	My symptoms were normal	☐	☐	☐	☐	☐
35	I thought most symptoms are harmless	☐	☐	☐	☐	☐
36	My symptoms changed quickly	☐	☐	☐	☐	☐
37	I thought nothing was wrong	☐	☐	☐	☐	☐
38	I thought it could be a sign of illness, because I am often ill	☐	☐	☐	☐	☐
39	I thought my symptoms were serious	☐	☐	☐	☐	☐
40	My symptoms were different to those I saw in a health campaign	☐	☐	☐	☐	☐
41	My symptoms were really severe	☐	☐	☐	☐	☐

Again, we are interested in symptoms which you think are related to your recent referral to hospital. For the following questions, please give an exact date if you can. Otherwise please give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

D) When did you **first think** about telling your GP, nurse or other healthcare professional about your symptom(s)?

Exact date:	OR	Estimated time after first noticing symptoms
dd/mm/yyyy		……. Day(s) ……. Week(s) ……..Month(s)

E) When did you **first tell** your GP, nurse or other healthcare professional about your symptom(s)?

Exact date:	OR	Estimated time after first noticing symptoms
dd/mm/yyyy		……. Day(s) ……. Week(s) ……..Month(s)

Appendix 20: 'Think Aloud' Task: Problems identified by participants (Face Validity; PaTH-Q Version Two)

Barriers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
1	**My symptoms were getting better**	P3					P5	P2, P4
2	**I could still do my everyday activities**	P3, P4		P2			P5	
3	**My symptoms were normal**	P3		P2			P5	P4
4	**I did not get more symptoms**	P2, P3					P5	P4
5	**I thought my symptoms were just due to my age**	P3, P4		P2			P5	
6	**I was still able to get out of bed**	P3, P4	P2				P5	
7	**Symptoms often get better on their own**	P3		P2	P4		P5	
8	**I often get these symptoms**	P3, P4		P2			P5	
9	**People at my age do get this type of symptom**	P2, P3, P4					P5	
10	**My symptoms started slowly**	P2, P3, P4					P5	

Barriers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
11	**It is normal for someone like me to get this symptom**	P2, P3, P4					P5	
12	**I thought my symptoms were temporary**	P2, P3, P4					P5	
13	**I was still able to move**	P2, P3, P4					P5	
14	**My symptoms were similar to symptoms I had in the past**	P2, P3, P4					P5	
15	**My symptoms changed slowly or not at all**	P2, P3, P4					P5	
16	**I am rarely ill**	P2, P3, P4					P5	
17	**I was in no pain**	P2, P3, P4					P5	
18	**I knew what had triggered my symptoms**	P2, P3, P4					P5	
19	**My symptoms were only mild**	P2, P3, P4					P5	
20	**My symptoms were difficult to notice**	P2, P3, P4					P5	

Barriers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
21	**My symptoms are common**	P2, P4				P3	P5	
22	**I thought my symptoms would get better on their own**	P2, P3, P4					P5	
23	**A friend or family member had similar symptoms which were not signs of illness**	P2, P3	P4				P5	
24	**I thought my symptoms would come and go**	P2, P3, P4					P5	
25	**I expected to get this type of symptom at my age**	P2, P3, P4					P5	
26	**I thought my symptoms would be short lived**	P3, P4			P2		P5	
27	**My symptoms were different to those I saw in a health campaign**	P2, P3, P4					P5	
28	**I understood my symptoms**	P2, P3				P4	P5	
29	**Nothing needed to be**	P2, P3, P4					P5	

Barriers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
	done about my symptoms							
30	**I am generally a healthy person**	P2, P3					P5	P4
31	**My symptoms were vague**	P2, P3, P4					P5	
32	**Most symptoms are harmless**	P2, P3, P4					P5	
33	**I was still able to eat**	P3, P4					P5	P2
34	**I thought nothing was wrong**	P2, P3, P4					P5	
35	**I expected to have these symptoms**	P2, P3, P4					P5	
36	**I thought my symptoms were not serious**	P2, P3, P4					P5	

Triggers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
1	**My symptoms were getting worse**	P2, P3, P4, P5						
2	**I could not do my everyday activities**	P2, P3, P4, P5						
3	**My symptoms were not normal**	P2, P3, P4, P5						
4	**I got more symptoms**	P2, P3, P4					P5	
5	**I thought my symptoms were due to illness rather than age**	P2, P3, P5						P4
6	**I was unable to get out of bed**	P2, P3, P4					P5	
7	**Symptoms rarely get better on their own**	P2, P3, P4, P5						
8	**I rarely get these symptoms**	P3, P4, P5		P2				
9	**People at my age do not get this type of symptom**	P2, P3, P4, P5						
10	**My symptoms started suddenly**	P2, P3, P4, P5						

Triggers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
11	**It is not normal for someone like me to get this symptom**	P2, P3, P5						P4
12	**I thought my symptoms were persistent**	P2, P3, P4						P5
13	**I was unable to move**	P2, P3, P4, P5						
14	**My symptoms were different to symptoms I have had in the past**	P2, P3, P4, P5						
15	**My symptoms changed quickly**	P2, P3, P4, P5						
16	**I am often ill**	P2, P3, P4, P5						
17	**I was in pain**	P2, P3, P4, P5						
18	**I did not know what had triggered my symptoms**	P2, P3, P4, P5						
19	**My symptoms were not mild**	P2, P3, P4, P5						
20	**My symptoms were easy to notice**	P2, P3, P4, P5						

Triggers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
21	**My symptoms were unusual**	P2, P3, P5				P4		
22	**I thought my symptoms were not getting better on their own**	P2, P3, P4, P5						
23	**A friend or family member had similar symptoms which turned out to be signs of illness**	P2, P3, P4, P5						
24	**I thought my symptoms should have been gone by then**	P5					P2	P3, P4
25	**I did not expect to get this symptom at my age**	P2, P3, P4, P5						
26	**I thought my symptoms would last a long time**	P2, P4						P3, P5
27	**My symptoms were similar to those I saw in a health campaign**	P2, P3, P4, P5						

Triggers to seeking help								
	Items	**No problems**	**Not applicable**	**Incongruent response**	**Different question**	**Confusion**	**Missing**	**Repeated question**
28	**I could not understand my symptoms**	P2, P4		P3				P5
29	**Something needed to be done about my symptoms**	P2, P3, P4, P5						
30	**My general health is not good**	P2, P3, P4, P5						
31	**My symptoms were striking**	P2, P3, P4, P5						
32	**Most symptoms are a sign of illness**	P2, P3, P5			P4			P5
33	**I was unable to eat**	P2, P3, P4, P5						
34	**I thought something was wrong**	P2, P3, P4, P5						
35	**I did not expect to have these symptoms**	P2, P3, P4, P5						
36	**I thought my symptoms were serious**	P2, P3, P4, P5						

Appendix 21: 'Think Aloud' Task: Problems identified by participants for each item (Face Validity; PaTH-Q Version Three)

	Items	No problems	Not applicable	Incongruent response	Different question	Confusion	Missing	Repeated question
1	**My symptoms started suddenly**	P1, P2, P3, P4						
2	**My symptoms lasted longer than I expected**	P1, P2, P3, P4						
3	**I was unable to move**	P1, P3, P4						P2
4	**I thought most symptoms are a sign of illness**	P1, P2, P3, P4						
5	**I got more and more symptoms**	P1, P2, P3, P4						
6	**My symptoms seemed to get better**	P1, P2, P3, P4						
7	**My symptoms were vague**	P1, P2, P3, P4						
8	**I was still able to get out of bed**	P1, P2, P3, P4						
9	**I was in pain**	P1, P2, P3	P4					
10	**I did not know what had triggered my symptoms**	P1, P2, P3, P4						
11	**I thought people at my age do not get this type of symptom**	P2, P3	P4					P1
12	**I thought my symptoms would get better on their own**	P1, P2, P3, P4						
13	**I thought it is normal for someone like me to get this symptom**	P1, P3, P4				P2		

	Items	No problems	Not applicable	Incongruent response	Different question	Confusion	Missing	Repeated question
14	**My symptoms changed slowly or not at all**	P1, P2, P3, P4						
15	**My symptoms were coming and going**	P1, P2, P3, P4						
16	**My symptoms were similar to symptoms I had in the past**	P1, P2, P3, P4						
17	**I did not expect to have these symptoms**	P1, P2, P3, P4						
18	**I thought my symptoms were common**	P1, P2, P3, P4						
19	**I was unable to eat**	P1, P2, P3, P4						
20	**I understood my symptoms**	P1, P2, P3, P4						
21	**My symptoms were easy to notice**	P1, P2, P3, P4						
22	**I could still do my everyday activities**	P1, P2, P3, P4						
23	**My symptoms were striking**	P1, P2, P3, P4						
24	**I thought my symptoms were just due to age rather than illness**	P1, P2, P3, P4						
25	**I thought my symptoms would be short lived**	P1, P2, P3, P4						
26	**My symptoms seemed unusual**	P1, P2, P3, P4						
27	**My symptoms were getting**	P1, P2, P3, P4						

	Items	No problems	Not applicable	Incongruent response	Different question	Confusion	Missing	Repeated question
	worse							
28	**My symptoms were persistent**	P1, P2, P3, P4						
29	**A friend or family member had similar symptoms which turned out to be signs of illness**	P1, P2, P3	P4					
30	**I thought something needed to be done about my symptoms**	P3, P4			P1			P2
31	**It was unlikely to be a sign of illness, because I am generally a healthy person**	P1, P2, P3, P4						
32	**I did not expect to get this symptom at my age**	P1, P2, P3, P4						
33	**My symptoms were only mild**	P1, P2, P3, P4						
34	**My symptoms were normal**	P1, P2, P4				P3		
35	**I thought most symptoms are harmless**	P2, P3, P4						P1
36	**My symptoms changed quickly**	P1, P3, P4						P2
37	**I thought nothing was wrong**	P1, P2, P3, P4						
38	**I thought it could be a sign of illness, because I am often ill**	P2, P3, P4	P1					
39	**I thought my symptoms were serious**	P2, P3, P4	P1					
40	**My symptoms were different to**	P1, P2, P3, P4						

	Items	No problems	Not applicable	Incongruent response	Different question	Confusion	Missing	Repeated question
	those I saw in a health campaign							
41	**My symptoms were really severe**	P1, P2, P3, P4						

Appendix 22: Expert Review Invitation Email (Content Validity; PaTH-Q Version Three)

Kummer, Sonja

From: Kummer, Sonja
Sent: 09 August 2016 15:51
To: [redacted]
Subject: Expert Review Study Invitation
Attachments: Pathways to Healthcare Questionnaire_ERS_090816.pdf

Dear [redacted]

In March 2016 you kindly agreed to serve as an expert reviewer to evaluate the "Pathways to Healthcare Questionnaire" (PaTH-Q), a theory-based questionnaire that can be used with patients who have sought help for potential symptoms of cancer, in order to assess the factors that contributed to their decision to seek help.

Based on the helpful feedback provided by you and other experts we have modified the PaTH-Q. Specifically, we have:

1) focused solely on heuristics and biases when people first notice symptoms rather than at different time points in the patient pathway.
2) deleted and replaced problematic items, such as reverse coded items.
3) added additional items to ensure that each heuristics category covers the full range of the definition.

I am now writing to ask you if you would be willing to serve as an expert panel reviewer for the modified questionnaire.

If you are happy to serve as an expert panel reviewer please find attached to this email the revised version of the PaTH-Q. To fill out the expert panel reviewer form please click here: https://kcldental.qualtrics.com/SE/?SID=SV_cCigN32hmVUsF9z . The form will take approximately 20 minutes to complete.

I would be very grateful if you could complete your feedback by September 9th 2016.

I look forward to your expertise and feedback to guide this process.

If you have any questions, or problems accessing the attached file or link, please do not hesitate to contact me.

Thank you for your time and consideration.

Kind Regards,

Sonja Kummer

Sonja Kummer
PhD Researcher
Population and Patient Health, Social and Behavioural Sciences Unit
Dental Institute
King's College London
18th Floor

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Appendix 23: Expert Review Rating Form (Content Validity; PaTH-Q Version Three)

Expert Reviewer Rating Form

Participant No.:

Instructions:

For the expert panel task, items relating to each heuristic have been grouped together (they are mixed up in the actual questionnaire). The definition of each heuristic is provided at the top of each page and the items are on the left-hand-side of the page.

Please read the definition of the heuristic, and then rate the items **using the shaded expert rating form** on the right-hand-side of the page.

Please rate each item as follows:

- The level of representativeness on a scale of 1 – 4.
- The level of clarity for each item, on a scale of 1 – 4.
- Whether or not an item should be deleted.

Space is provided for you at the end of each section to make any additional comments.

'Rate of Change' Heuristic

The following questions aim to assess the influence of the **'rate of change'** rule/heuristic. This heuristic states that:
Symptoms that are worsening, unstable, or increasing in number, and symptoms that have a sudden rather than gradual onset, can indicate illness and provide motivation to seek help promptly. In comparison, symptoms that are getting better/improving, fluctuating, stable, or decreasing in number, can indicate absence of illness and reduce motivation to seek help promptly.

At the start...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	Representativeness **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	Clarity **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Inclusion Do you think the item should be deleted?
My symptoms seemed to get better						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were getting worse						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms changed slowly or not at all						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms changed quickly						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I got more and more symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms started suddenly						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Severity' Heuristic

The following questions aim to assess the influence of the '**severity**' rule/heuristic. This heuristic states that:
Symptoms that disrupt functioning indicate the presence of illness and/or the need for care whereas those that allow normal functioning will reduce motivation to seek help.

						Representativeness	Clarity	Inclusion
At the start...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
I could still do my everyday activities						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I was still able to get out of bed						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I was unable to eat						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I was unable to move						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Age-illness' Heuristic

The following questions aim to assess the influence of the **'age-illness'** rule/heuristic. This heuristic states that:
As individuals grow older, they increasingly attribute sensations to the ageing process rather than to illness.

						Representativeness	Clarity	Inclusion
At the start...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
I thought people at my age do not get this type of symptom						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought my symptoms were just due to age rather than illness						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought it is normal for someone like me to get this symptom						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I did not expect to get this symptom at my age						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Novelty' Heuristic

The following questions aim to assess the influence of the **'novelty'** rule/heuristic. This heuristic states that:
Symptoms that are new, different, or incongruent (unexpected) with underlying schema rather than familiar, common, or similar to a co-existing chronic illness can be a key motivator to seek help.

						Representativeness	Clarity	Inclusion
At the start…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
My symptoms seemed unusual						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
My symptoms were similar to symptoms I had in the past						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I did not expect to have these symptoms						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I thought my symptoms were common						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Pattern' Heuristic

The following questions aim to assess the influence of the **'pattern'** rule/heuristic. This heuristic states that:
Compared to symptoms that are striking, severe or extreme, symptoms that are diffuse, mild, ambiguous or vague lead to greater numbers of comparisons; in turn, there is more chance of error and more susceptibility to changed interpretations. Thus, diffuse, mild, ambiguous or vague symptoms are less likely to be interpreted as indicators of illness or in need of prompt medical care

At the start...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
I was in pain						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were only mild						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were easy to notice						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were vague						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were striking						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were really severe								

ADDITIONAL COMMENTS/ITEMS:

'Duration' Heuristic

The following questions aim to assess the influence of the '**duration**' rule/heuristic. This heuristic states that:
Symptoms that are persistent or prolonged (compared to previous experience or expectations), rather than short lived or intermittent, can indicate a level of seriousness, which in turn, can be a reason for seeking help.

						Representativeness	Clarity	Inclusion
At the start…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**1** = item is not representative **2** = item needs major revisions to be representative 3 = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear 3 = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
I thought my symptoms would get better on their own						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I thought my symptoms would be short lived						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I thought my symptoms were coming and going						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
My symptoms lasted longer than I expected						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
My symptoms were persistent						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Symmetry' Heuristic

The following questions aim to assess the influence of the '**symmetry**' rule/heuristic. The heuristic states that:
Detection of bodily changes stimulates labelling, attributing a cause, explanation or reason for the change.

At the start...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
A friend or family member had similar symptoms which turned out to be signs of illness						**1 2 3 4**	**1 2 3 4**	**Yes / No**
My symptoms were different to those I saw in a health campaign						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I understood my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I did not know what had triggered my symptoms						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Optimistic bias' Heuristic

The following questions aim to assess the influence of the '**optimistic bias**' rule/heuristic. This heuristic states that:
Individuals have a generally optimistic bias in that their interpretations, in keeping with previous experience, and will tend to make innocuous explanations rather than those that are life threatening

At the start…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**Representativeness** **1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**Clarity** **1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	**Inclusion** Do you think the item should be deleted?
It was unlikely to be a sign of illness, because I am generally a healthy person						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought it could be a sign of illness, because I am often ill						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought most symptoms are harmless						**1 2 3 4**	**1 2 3 4**	**Yes / No**
I thought most symptoms are a sign of illness						**1 2 3 4**	**1 2 3 4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

'Reasons to consider seeking help'

The following questions aim to assess the influence of '**Reasons to consider seeking help'.** The definition states that:
The time point at which an individual believes they have a motive to consult a Healthcare Professional (HCP) about their symptoms and thus consider seeking help from a HCP. Reasons for discussing symptoms with a HCP may be due to cognitive factors (e.g. beliefs about symptoms, nothing/something is wrong / serious).

						Representativeness	Clarity	Inclusion
At the start…	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	**1** = item is not representative **2** = item needs major revisions to be representative **3** = item needs minor revisions to be representative **4** = item is representative	**1** = item is not clear **2** = item needs major revisions to be clear **3** = item needs minor revisions to be clear **4** = item is clear	Do you think the item should be deleted?
I thought my symptoms were serious						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I thought something needed to be done about my symptoms						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
I thought nothing was wrong						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**
My symptoms were normal						**1 2** 3 **4**	**1 2** 3 **4**	**Yes / No**

ADDITIONAL COMMENTS/ITEMS:

The measure is designed to assess how various heuristics lead individuals to form a representation about symptoms and/or whether symptoms merit medical care. Do you think the questionnaire represents the entire domain of heuristics?

☐ Yes

☐ No

Are there any constructs that you think this instrument missed? *Please provide any additional comments in the space provided.*

Appendix 24: PaTH-Q Version Four

The Pathways To Healthcare Questionnaire

Try to answer all the questions

All the information you give will be treated in the strictest confidence

Once you have completed the questionnaire you should post it using the FREEPOST envelope provided

For further information please contact:
Sonja Kummer
King's College London Dental Institute
Department of Population & Patient Health
Guy's Hospital, Tower Wing, Floor 18
Great Maze Pond
London SE1 9RT
Tel.: 020 7188 1161

Section 1 – About your symptoms

The following questions are about when you first noticed a symptom and when you first told your a healthcare professional (GP, nurse, dentist) about it. Please give an exact date if you can. Otherwise please give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

We are interested in the symptom(s) which you think were related to your diagnosis of cancer.

A) What was the first thing or symptom(s) you noticed?

B) When did you first notice this?

Exact date: *dd/mm/yyyy*

OR

Estimate:

C) Think back to the time when you first noticed your symptom(s). Please indicate the extent to which you agree with the following statements:

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
1	At the start, my symptoms seemed to get better	☐	☐	☐	☐	☐
2	At the start, I was in pain	☐	☐	☐	☐	☐
3	I did not expect to get this symptom at my age	☐	☐	☐	☐	☐
4	At the start, my symptoms seemed unusual to me	☐	☐	☐	☐	☐
5	At the start, I thought people at my age do not get this type of symptom	☐	☐	☐	☐	☐
6	My symptoms did not change	☐	☐	☐	☐	☐

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
7	At the start, I thought nothing was wrong	☐	☐	☐	☐	☐
8	At the start, I was still able to pursue my hobbies or other leisure activities	☐	☐	☐	☐	☐
9	At the start, I had trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase	☐	☐	☐	☐	☐
10	My symptoms were persistent	☐	☐	☐	☐	☐
11	At the start, my symptoms were only mild	☐	☐	☐	☐	☐
12	At the start, my symptoms were different to those I saw in a health campaign	☐	☐	☐	☐	☐
13	At the start, I thought it is normal for someone my age to get this symptom	☐	☐	☐	☐	☐
14	At the start, my symptoms were getting worse	☐	☐	☐	☐	☐
15	At the start, I got more and more symptoms	☐	☐	☐	☐	☐
16	I think most symptoms are harmless	☐	☐	☐	☐	☐
17	At the start, my symptoms were similar to symptoms I had in the past	☐	☐	☐	☐	☐
18	At the start, I thought my symptoms would be short lived	☐	☐	☐	☐	☐
19	At the start, my symptoms changed quickly	☐	☐	☐	☐	☐
20	At the start, I needed to stay in bed or a chair during the day	☐	☐	☐	☐	☐
21	At the start, I thought my symptoms were not normal	☐	☐	☐	☐	☐
22	At the start, my symptoms were vague	☐	☐	☐	☐	☐
23	My symptoms lasted longer than I expected	☐	☐	☐	☐	☐
24	My symptoms started suddenly	☐	☐	☐	☐	☐
25	At the start, I thought I understood my symptoms	☐	☐	☐	☐	☐

		Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
26	At the start, I thought my symptoms would get better on their own	☐	☐	☐	☐	☐
27	At the start, I did not expect to have these symptoms	☐	☐	☐	☐	☐
28	At the start, I thought my symptoms were coming and going	☐	☐	☐	☐	☐
29	At the start, my symptoms were striking	☐	☐	☐	☐	☐
30	At the start, I needed to rest	☐	☐	☐	☐	☐
31	At the start, I thought my symptoms were just due to age rather than illness	☐	☐	☐	☐	☐
32	At the start, my symptoms were easy to notice	☐	☐	☐	☐	☐
33	At the start, I did not know what had triggered my symptoms	☐	☐	☐	☐	☐
34	A friend or family member had similar symptoms which turned out to be signs of illness	☐	☐	☐	☐	☐
35	At the start, I thought something needed to be done about my symptoms	☐	☐	☐	☐	☐
36	At the start, I thought my symptoms were common	☐	☐	☐	☐	☐
37	I think most symptoms are a sign of illness	☐	☐	☐	☐	☐
38	At the start, I thought it could be a sign of illness, because I am often ill	☐	☐	☐	☐	☐
39	At the start, I was still able to do my work or other activities	☐	☐	☐	☐	☐
40	At the start, my symptoms were really severe	☐	☐	☐	☐	☐
41	At the start, I thought my symptoms were serious	☐	☐	☐	☐	☐
42	At the start, I thought it was unlikely to be a sign of illness, because I am generally a healthy person	☐	☐	☐	☐	☐

D) Below are a number of words that describe different feelings and emotions. Again, think back to the time when you first noticed your symptom(s). Please indicate the extent to which you agree with the following statements.

When I first noticed my symptom(s), I felt

		Not at all	A little bit	Moderately	Quite a bit	Very much
1	Anxious	☐	☐	☐	☐	☐
2	Afraid	☐	☐	☐	☐	☐
3	Distressed	☐	☐	☐	☐	☐
4	Concerned	☐	☐	☐	☐	☐
5	Scared	☐	☐	☐	☐	☐

E) When did you <u>first think</u> about telling your GP, nurse or dentist about your symptom(s)?

Exact date:
dd/mm/yyyy

OR

Estimated time after first noticing symptoms
…….. Day(s)
…….. Week(s)
……..Month(s)

F) When did you <u>first tell</u> your GP, nurse or dentist about your symptom(s)?

Exact date:
dd/mm/yyyy

OR

Estimated time after first noticing symptoms
…….. Day(s)
…….. Week(s)
……..Month(s)

G) What type of cancer did you have?

Section 2 – About you

The next questions relate to general information about you. This will help us to understand more about you and your answers to the questions so far.

A) What is your age?

……

B) What is your gender?

Male	☐	Female	☐

C) Which best describes your employment status? Please tick one box only

Employed full-time	☐	Retired	☐
Employed part-time	☐	Student	☐
Self-employed full-time	☐	Permanently sick/disabled	☐
Self-employed part-time	☐	Temporarily sick/disabled	☐
Unemployed (seeking work)	☐	Looking after your family/home	☐
Unemployed (not seeking work)	☐	Other, please specify: ……	☐

D) What is your highest level of qualification? Please tick one box only

Degree (or equivalent)	☐	GCSE/ O' Level	☐
Diploma (or equivalent)	☐	None	☐
A' Level	☐	Other, please specify: ……	☐

E) How would you describe your ethnicity? Please tick one box only

White		**Asian or Asian British**	
British	☐	Indian	☐
Irish	☐	Pakistani	☐
Any other white background:	☐	Bangladeshi	☐
Mixed		Any other Asian background:	☐
White and Black Caribbean	☐	**Black or Black British**	☐
White and Black African	☐	Caribbean	☐
White and Asian	☐	African	☐
Any other Mixed background:	☐	Any other Black background:	☐
Chinese or other ethnic group			
Chinese	☐		
Any other ethnic group:	☐		

I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be treated in accordance with the terms of the UK Data Protection Act 1998. .....☐

Thank you!

Please post this questionnaire back to the researcher in the FREEPOST envelope provided (no stamp needed)

If you need support or information connected to your cancer experience contact your doctor. You can also speak to:

Macmillan Cancer Support [Telephone 0808 808 00 00; available Monday – Friday 9.00am - 8.00pm]

Cancer Research UK Nurses [Telephone 0808 800 40 40; available Monday - Friday 9.00am - 5.00pm]

Appendix 25: Test-retest reliability details (Study Four)

Test re-test reliability testing of the PaTH-Q was performed by an intercalated BSc in Psychology student (supervised by SK and SS). The findings were as follows:

The ICC scores revealed high test-retest reliability for *Rate of Change rule* (ICC = 0.81), *Novelty rule* (ICC = 0.86), *Severity rule* (ICC = 0.93), *Pattern rule* (ICC = 0.84), *Duration rule* (ICC = 0.91) and 'cognitive reasons to consider help-seeking' (ICC = 0.89). The ICC scores were below the ideal cut-off for *Age-Illness rule* (ICC = 0.74) and *Optimistic Bias rule* (ICC = 0.70). Further analysis using Cohen's Kappa scores revealed slight to moderate scores for *Age-illness rule* (κ = 0.15-0.46) and *Optimistic Bias rule* (κ = 0.25-0.32). Repeated measures ANOVA demonstrated a non-significant effect for responding late to the second questionnaire and the change in total score per heuristic (all $p > 0.05$).

Appendix 26: Example of Involvement Opportunity (Study Four)

First thoughts about symptoms of cancer: Test a questionnaire

Why do we need you?

We have recently designed a new questionnaire that measures what people first thought about symptoms which turned out to be signs of cancer. We are interested in this because what people think about their symptoms may affect their decision to seek help from a healthcare professional. The purpose of this study is to check that the new questionnaire is dependable (reliable) or measures what it is supposed to measure (valid). To check this we would like to invite adults who have experienced symptoms of cancer to complete the questionnaire twice.

Who are we looking for?

- People who have had cancer (recently or in the past) themselves.
- You had symptoms that turned out to be signs of cancer
- You noticed the symptom(s) yourself
- You are over 18 years of age

What can you gain from this opportunity?

- The chance to share your cancer experience
- Help test the new questionnaire
- £10 voucher for each questionnaire you complete

What will happen if you decide to take part?

- You will be asked to complete a questionnaire on two occasions.
- The questionnaire should take about 20 minutes to complete.
- You will be asked questions about your first symptoms. For example, did your symptoms start suddenly? At the start, did you think something was wrong?
- You can complete the questionnaire online or on a paper copy.
- One month after you have completed the first questionnaire, we will ask you to complete it again.

Is there an induction and training?

- This role does not require formal induction or training

What support is offered?

- You can contact the research team by email, phone or post at any point, to ask questions about the study.
- We don't expect that this questionnaire will cause you any distress. However, we understand that thinking about your experience of cancer can be a sensitive topic. If you feel upset, please stop completing the questionnaire. If you need support or information connected to your cancer experience, contact your doctor. You can also speak to Macmillan Cancer Support (Telephone 0808 808 00 00; available Monday – Friday 9.00am - 8.00pm) or Cancer Research UK Nurses (Telephone 0808 800 40 40; available Monday - Friday 9.00am - 5.00pm).

Detailed information about this study can be found in the participant information sheet (https://kcldental.eu.qualtrics.com/CP/File.php?F=F_b3NKKeWgOz0D1U9)

Appendix 27: Invitation Email (Study Four)

Email to Potential Participants

Thank you for your interest in this study.

Please find attached to this email an information sheet which provides further details about the study. Before you decide if you would like to take part, it is important that you read this carefully.

To take part and fill out the questionnaire please click here: https://kcldental.qualtrics.com/SE/?SID=SV_38KA2wk4oSJzFsx

You will be asked to enter your unique identification number, which is **XXX**

If you have any further questions, or if you would prefer to complete this questionnaire by post, please do not hesitate to contact me either by replying to this email or by telephone: 020 3299 5171

Thank you for your time and consideration.

Yours sincerely

Sonja Kummer

Appendix 28: Information Sheet (Study Four)

Information Sheet for Participants

REMAS Reference Number: LRS-16/17-3769

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

KING'S College LONDON

Validation of the Pathways to Healthcare Questionnaire (PaTH-Q)

I would like to invite you to participate in this research project which forms part of my PhD research. You should only participate if you want to: choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. **Please ask me if there is anything that is not clear or you would like more information.**

What is the purpose of the study?
I have recently designed a new questionnaire that measures what people first thought about symptoms which turned out to be signs of cancer. I am interested in this because what people think about their symptoms may affect their decision to seek help from a healthcare professional. We do not know if the new questionnaire [the Pathways to Healthcare Questionnaire (PaTH-Q)] is reliable or measures what it is supposed to measure (valid). The purpose of this study is to test the PaTH-Q. To do this I would like people to complete the questionnaire twice. Using statistical tests we will be able to check the questionnaire for signs of reliability and validity.

Why have I been invited to take part?
We would like to test the PaTH-Q with people who experienced symptoms that turned out to be signs of cancer. In order to take part in this study is necessary that you noticed the symptom(s) yourself, you are over 18, you understand English and have been diagnosed with cancer recently or in the past.

Do you have to take part?
No. Participation is voluntary. You do not have to take part. You should read this information sheet and if you have any questions you should ask the research team.

What will happen to me if I take part?
If you decide you would like to participate, then you will be given this information sheet to keep. You will be asked to complete a questionnaire on two occasions. Questions asked will be about the symptoms which were related to your diagnosis of cancer. For example, you will be asked about the first thing or symptom(s) you noticed, if your symptoms started suddenly, if your symptoms stopped you doing your daily activities and what you thought about your symptoms (for instance, at the start, did you think something was wrong?). You will also be asked about how you felt when you first noticed your symptom(s), your age, ethnicity, employment status, education and what type of cancer you have had. The questionnaire should take about 20 minutes to complete. If you submit a completed questionnaire we will accept this as your consent to participate.

You can complete the questionnaire online or on a paper copy. If you complete a paper copy, please return it to us in the freepost envelope provided (no stamp needed).

One month after you have completed the questionnaire, we will ask you to complete it again. For both questionnaires, if you do not complete it within 2 weeks, we will send a reminder to check if you would still like to take part in the research.

Even if you have decided to take part, you are still free to stop your participation at any time and to have research data/information relating to you withdrawn without giving any reason up to 1st March 2017, when I will have written up my report.

Incentives
After you have completed and submitted each questionnaire you will be sent a £10 Amazon gift card to thank you for your participation in this research project.

What are the possible benefits and risks of taking part?
There is no immediate benefit to you as a participant.

We understand that thinking about your experience of cancer can be a sensitive topic. If you feel upset, please stop completing the questionnaire. If you need support or information connected to your cancer experience, contact your doctor. You can also speak to Macmillan Cancer Support (Telephone 0808 808 00 00; available Monday – Friday 9.00am - 8.00pm) or Cancer Research UK Nurses (Telephone 0808 800 40 40; available Monday - Friday 9.00am - 5.00pm).

Will my taking part be kept confidential?
Yes. I will ask for your contact details (email address or postal address) in order to send you the questionnaire. This information will be kept separately to the questionnaire and destroyed once the study is complete.

The questionnaires will not record your name or any other personal data such as your address or date of birth. No data will be accessed by anyone other than the research team; and anonymity of the material will be protected by using a unique code rather than your name. It will not be possible to identify you from the results.

The UK Data Protection Act 1998 will apply to all information gathered for the study and held on password-locked computer files and locked cabinets within King's College London. Questionnaires will be stored securely and destroyed after three years.

Who is organising and funding the research?
The study is being undertaken by a postgraduate research student (Miss Sonja Kummer) at King's College London Dental Institute towards a doctoral (PhD) degree. A Dental Student (Ms Anna Beavan), who studying for an intercalated degree in psychology is also working on this study as part of her research project. This study is funded by King's College London Dental Institute, and has been approved by the King's College London Research Ethics Committee.

What will happen to the results of the study?
The results will be written up as part of a doctoral thesis and for an intercalated degree in psychology research project. I also hope to publish the results in an academic journal and disseminate the research findings at academic conferences. You can get a copy of the final report from Sonja Kummer if you wish (please contact sonja.kummer@kcl.ac.uk). You will not be identified in any report or publication.

Who should I contact details for further information?
If you have any questions or require more information about this study please contact me using the following contact details:

Sonja Kummer
King's College London
Dental Institute
18th Floor, Tower Wing
Guy's Hospital
SE1 9RT
Email: sonja.kummer@kcl.ac.uk
Telephone: 020 3299 5171

What if something goes wrong?
If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice or information:

Dr Suzanne Scott
Senior Lecturer
King's College London Dental Institute
18th Floor, Tower Wing
Guy's Hospital
SE1 9RT
Email: suzanne.scott@kcl.ac.uk

Telephone: 020 7188 1161

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 29: Eligibility Assessment (Study Four)

Eligibility Assessment

1. Are you over 18 years of age?		
Yes	❑	
No	❑	*
2. Have you ever had cancer (recently or in the past)?		
Yes	❑	
No	❑	*
3. Which of the following best describes the event(s) which led to your diagnosis of cancer? *(Please place a cross in ONE box only)*		
• I had symptoms or noticed a change in my body and went to see a GP/family doctor/dentist or nurse.....	❑	
• I had symptoms or noticed a change in my body and attended A&E (Accident and Emergency).....	❑	
• My cancer was discovered by chance, while I was being investigated or monitored by a doctor for something else.....	❑	*
• As part of a test offered by the National Health Service - I took part in a screening programme.....	❑	*

* **If this box was checked participants were directed to the end of the questionnaire where they received the following message:**

Thank you for your interest in taking part in this research study. Unfortunately your response indicates that our questionnaire is unsuitable for you to fill in. Please look out for future opportunities to take part in cancer research and thank you again for your interest.

Appendix 30: KCL Ethical Approval (Study Four)

Research Ethics
Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4078/4077
reo@kcl.ac.uk

KING'S College LONDON

Sonja Kummer

31 October 2016

Dear Sonja

LRS-16/17-3769 - Validation of the Pathways to Healthcare Questionnaire (PaTH-Q)

I am pleased to inform you that full approval for your project has been granted by the BDM Research Ethics Panel

- Ethical approval is granted for a period of **three years** from 31 October 2016 . You will not receive a reminder that your approval is about to lapse. It is your responsibility to apply for an extension prior to the project lapsing.
- You should report any untoward events or unforeseen ethical problems to the panel Chair, via the Research Ethics Office, within a week of occurrence. Information about the panel may be accessed at: http://www.kcl.ac.uk/innovation/research/support/ethics/committees/sshl/reps/index.aspx
- If you wish to change your project or request an extension of approval, please complete and submit a Modification Request to cree-lowrisk@kcl.ac.uk. Please quote your ethics reference number, found at the top of this letter, in all correspondence with the Research Ethics Office. Details of how to complete a modification request can be found at: http://www.kcl.ac.uk/innovation/research/support/ethics/applications/modifications.aspx
- All research should be conducted in accordance with the King's College London *Guidelines on Good Practice in Academic Research* available at: http://www.kcl.ac.uk/college/policyzone/assets/files/research/good%20practice%20Sept%2009%20FINAL.pdf

Please note that we may, for auditing purposes, contact you to ascertain the status of your research.

We wish you every success with your research.

Best wishes,

BDM Research Ethics Panel REP Reviewers

22 December 2016

Dear Sonja,

Reference Number: RESCMR-16/17-3769

Study Title: Validation of the Pathways to Healthcare Questionnaire (PaTH-Q)

Modification Review Outcome: Full Approval

Thank you for submitting a modification request for the above study. This is a letter to confirm that you're request has now been granted Full Approval.

If you have any questions regarding your application please contact the Research Ethics Office at rec@kcl.ac.uk.

Kind regards,

Research Ethics Office
on behalf of

BDM Research Ethics Subcommittee

Appendix 31: Assessment of suitability of data for Factor Analysis (Study Four)

Heuristics:

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.130
Bartlett's Test of Sphericity	Approx. Chi-Square	1199.464
	df	703
	Sig.	.000

'Cognitive reasons to consider help-seeking': [36]

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.764
Bartlett's Test of Sphericity	Approx. Chi-Square	59.823
	df	6
	Sig.	.000

[36] Studies have proposed that at least three to five items are required to define a factor (Fabrigar and Wegener, 2012, Froman, 2001). Nevertheless, although KMO and Bartlett's test of sphericity indicated that the data would be suitable for factor analysis, Fabrigar and Wegener (2012) and Froman (2001) noted that the researcher should include at least five items to define a factor in the event that some items fail to load onto their expected factor. As such, based on this rationale, it was not possible to perform a Factor Analysis for 'cognitive reasons to consider help-seeking'.